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ABSTRACT

This monograph describes Families First, a family-designed system of mental health care for children in Essex County, New York. Philosophical principles of family-driven service delivery are outlined and illustrated with comments from participants. The planning that went into developing the Families First program is described, including initial outreach and funding, interviews with family members to assess their needs, and the establishment of a parent planning committee and an interagency task force. Priorities identified by families include respite care; advocacy services; information and referral; parent and sibling support; a family center; crisis services; and assistance with transportation, telephone connections, and medication costs. Provisions developed to meet each of these needs are described, as are social and recreational events, individualized family planning meetings, youth activities, and the project's newsletter. Principles established through the program's experiences are then summed up, including full inclusion of families as service designers, elimination of waiting lists, meaningful record keeping, and creative use of existing resources. Barriers to implementation of such programs are identified and discussed, followed by frequently asked questions and advice from parents. An appendix lists suggested materials to help launch such programs. (Contains 59 references.) (PB)

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Families at the Center

of the Development

of a System of Care

National Technical Assistance Center for Children's Mental Health

Center for Child Health and Mental Health Policy

Georgetown University Child Development Center

Funded by:
The Child, Adolescent and Family Branch

Center for Mental Health Services

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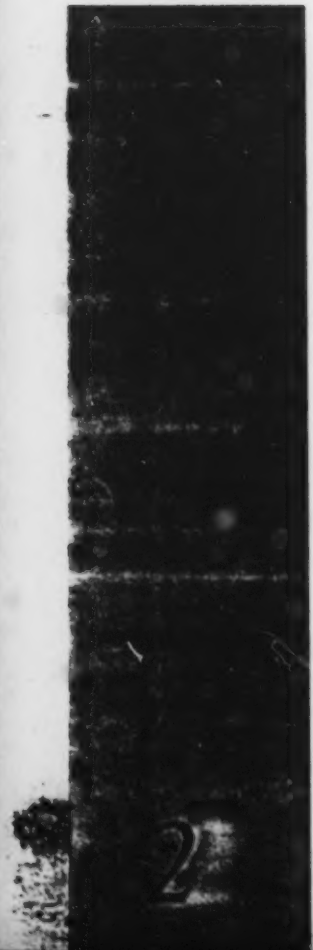
Naomi Tannen



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The development of Families First in Essex County was possible only because of the faith of so many individuals who believed in the vision and were willing to take a risk to support it.

The ongoing operation of the agency is possible because of the efforts and contributions of countless people. It is always humbling to realize that a whole community has given time, energy, material assistance, and creativity to make Families First what it is. How is it possible to list all of these contributors by name? The 83-year-old woman who bakes for our meetings and has offered her love to several young children; the potter who volunteered her time to teach an art class to four children; the families who have given holiday gifts to our participants and food for our food shelf; the small business people who have donated goods to our raffles; the participants who have given so generously to each other—their outgrown clothes, transportation, time on the phone; consultants from around the country who have given support when I was discouraged; volunteers; crisis and respite workers; and hotel owners who have donated rooms to provide respite to families who need it... The list is truly endless, and I am so grateful.

There are those whose names must be mentioned, because they have sustained the organization and have been an integral part of the family of Families First:

Mary Evans, Mary Armstrong, Fiona Thompson, and Gloria Newton-Logsdon at the New York State Office of Mental Health.

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Staff Members: Anne Mancini, John Sweeney, JoAnne Caswell, Linda Deal, Priscilla Hurd, and part-timers Shelley Fracalossi, Jim Karr, Diane Dier, Wanda Skopayko, Dwight James, and Eliza Pillard.

Board Members: Sandra Murphy (President), Ken White, Melody Hyatt, Tammi Wrest, Elizabeth Scully, Atea Ring, Ginene Carroll, Ruth Fowler, Mary Anne Brody, Jim Russ, Sue Peterson, Sarah Pachla, Kerri Klugman, Doug Dornan, Lynn Edmonds, Karen Robillard, and Kathy Scott.

A true community is like a quilt that provides warmth and comfort because of the thousands of threads that are intricately woven together. May all those who are part of the weaving know that their efforts have been deeply appreciated and that I say a heartfelt THANK YOU!

Naomi Tannen
Executive Director
Families First in Essex County
Elizabethtown, NY

Foreword

It has been over a decade since the Child and Adolescent Service System Program (CASSP) was established in response to Jane Knitzer's seminal study, *Unclaimed Children*, which documented the failure of service systems in this country to adequately serve children in need of mental health services and their families. The primary goals of the CASSP initiative were to develop a comprehensive service array, to increase collaboration among the major child-serving agencies, to strengthen the focus on children in mental health systems, to ensure that services are culturally competent, and to increase family involvement in the planning and development of service systems, treatment options, and individual service plans for children and adolescents with serious emotional disturbances.

From the CASSP initiative emerged the concept of a comprehensive, coordinated "system of care" for children with emotional disturbances and their families. Those familiar with the system of care concept know that it represents a philosophy and a framework for service delivery which emphasizes:

> *Child-serving agencies collaborating with each other and with families as partners to create a more seamless service system;*
>
> *The availability of a comprehensive array of treatment interventions and supports "wrapped around" children and families;*

Services that are provided in the communities where children and families live;

Services that are individualized to meet the needs of each child and family; and

Services that address the racial and ethnic differences of each family in a culturally competent manner.

The system of care philosophy has achieved wide acceptance, but change and system reform are difficult to achieve. Implementing this service delivery concept and philosophy requires people to think differently and to do business differently from the way they have in the past, often in contrast to what their training may have prescribed. However, in the last 12 years there has been tremendous progress—more and more communities are developing systems of care that are guided by this philosophy.

Many important steps have been taken towards implementing the goal of developing meaningful family input and of creating systems of care in which children and families are truly at the center. One important milestone was the Families as Allies regional conferences conducted from 1986 to 1988 by the Research and Training Center on Family Support and Children's Mental Health at Portland State University and by CASSP. These conferences were designed to develop state action plans to support family-professional collaboration in service delivery and system reform. A second milestone was the creation of the Federation of Families for Children's Mental

Health in 1989. But most significant in enhancing family participation and involvement have been the many committed individuals, families, and organizations across this country who have provided the foundation for moving this agenda forward and for changing the role of families.

One of these individuals is Naomi Tannen. In 1992, at a meeting held for the Robert Wood Johnson Foundation's Mental Health Services Program for Youth, Naomi presented her work with Families First and her partnership with families in a rural area of the Adirondacks in New York to develop a system of care driven by what families said they needed and wanted. Several families attending Naomi's session, some with tears in their eyes, stated that they wished someone had asked them those questions when they were seeking help for their children. I asked Naomi to document the experience of Families First so that she and the families of Essex County, New York, could share with other communities the experiences they have had in developing a system of care that is designed by families for families.

This document builds on the work of many other pioneers in the movement to develop systems of care that are child- and family-centered. It also breaks new ground in describing the implementation of a paradigm shift where, instead of families being blamed and stigmatized for their children's mental health problems, they become active participants in the development of services for their children. This shift is not easy. Systems change is enormously hard work and represents a dynamic process. As such, this document reflects a work in progress. Naomi and the families of Families First have shared in a very honest way the lessons they are learning.

Like *A System of Care for Severely Emotionally Disturbed Children & Youth* by Stroul and Friedman (1986) and *Towards a Culturally Competent System of Care* by Cross, Bazron, Dennis, and Isaacs (1989), two other seminal documents of the Georgetown University Child Development Center, *Families at the Center of the Development of a System of Care* provides a framework, principles, and strategies for a new way of thinking and for new ways of working with families. All of these documents have been on the cutting edge of system reform. Our hope is that this document and the experience of Families First will inspire other families and communities across this country to put families and children truly first.

There is no way to adequately acknowledge all the people who have played such critical roles in the family movement. Progress could not have occurred without the courage of families with children with emotional and behavioral disorders stepping forward to tell their stories and to work for system change, no matter the difficulties or the burden. Federal leadership also has played an important role in supporting families to achieve these goals—Ira Lourie, Judith Katz Leavy, Naomi Karp, Gary DeCarolis, Bill Quinlan, and Velva Spriggs have been strongly committed to supporting this vision. Barbara Friesen and her staff at the Research and Training Center on Family Support and Children's Mental Health at Portland State University, Barbara Huff and the membership of the Federation of Families for Children's Mental Health, and Carolyn Sanger and members of the National Alliance for the Mentally Ill, Child and Adolescent Network, all have provided knowledge, dedication, leadership, and support to promote and sustain the family advocacy movement. And, fortunately, in states and communities across the nation, there are now many family leaders.

We are very grateful to the Child, Adolescent and Family Branch of the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration, Department of Health and Human Services (DHHS), for funding support for this publication as well as for providing ongoing leadership in improving systems of care for children with emotional disturbances and their families across the country.

Thanks is also due to Scott Bryant-Comstock for his family-friendly design of this document and to Marie Keefe and Cappie Morgan of Counterparts for their always sensitive and competent editing.

Finally, our most sincere gratitude must be conveyed to Naomi Tannen for her vision, tenacity, hope, and belief in the strength and wisdom of families as well as to the families of Families First for guiding us on this path to respecting families and putting families and children first.

Sybil K. Goldman
National Technical Assistance Center for Children's Mental Health
Georgetown University Child Development Center

Preface

I began working full time with children who have emotional or behavioral disabilities in 1957. Since then, I have been: a special education teacher, a director of a small therapeutic community for adolescents with serious emotional problems, the coordinator of youth and family services at a county mental health center in Vermont, and a consultant and trainer in home- and community-based services. My work has always felt like a "calling," an opportunity to make a small contribution to what in Hebrew is called "tikkun olam," repairing the world. My commitment has been to a value system based on respect for the coping mechanisms developed by people in pain, the need to be open and honest in all interactions, and the desire to be flexible and responsive to each individual's needs and strengths. Through my experience, I have come to believe that hope is a prerequisite for healing, and that those offering assistance need to be guided by a fierce determination to succeed, as well as by humility and an openness to learning and growth.

New learnings emerge that suddenly seem self-evident as I evolve personally and professionally. How could I have missed it before? Fortunately, life offers us opportunities to utilize new skills and insights, and to try again.

After working in Vermont for 13 years helping to develop a system of care for families of children with emotional, behavioral, or mental disorders, I came to realize that I had made a very serious omission during the planning process. Although the programs that emerged were "family friendly," they were almost completely designed by service providers. In the mid to

late 1980s, consciousness raising began to take place in the area of consumer empowerment. The Child and Adolescent Service System Program (CASSP) emphasized the value of "child and family-centered" programs; the Portland Research and Training Center for Family Support and Children's Mental Health was established, and the Federation of Families for Children's Mental Health and the Alliance for the Mentally Ill, Child and Adolescent Network were formed. Family members' voices began to be heard.

It seemed that the next logical step would be to try to develop a local system of care in response to what families said they needed and wanted. If services were to be truly responsive to families, it made sense that families should be the primary designers and implementers of those services. The extremely rural, resource-poor area where I had lived for many years seemed to be the perfect laboratory in which to test this model.

This monograph tells the story of efforts to establish a family-designed system of care in the Adirondack Mountains in Essex County, New York. The planning began in January 1991 and Families First in Essex County opened its doors in November 1992.

This is not a "how-to" manual, but rather a report on a work in progress. Systems change is always an extremely challenging process. Along with times of deep satisfaction, there have been frequent times of frustration and self-doubt. Although the concept of a family-centered system may seem obvious to some, many people are skeptical about its efficacy. I urge those with doubts to turn to the "Questions Most Frequently Asked" section in Chapter III, Maintaining the Vision, and to understand that we are addressing these questions throughout this monograph.

I want to express my deep appreciation to the many teachers who have been instructive and supportive on this journey. My work has been influenced by so many of them: directors and staff of exemplary programs, researchers, and trainers. Their work has blended with mine. I am indebted to them for their insights and apologetic for not being able to give sufficient and specific credit to each one.

There are those without whom this project would not have been possible. The staff, board, and participants of Families First are unquestionably the backbone of the project. We have also been supported by countless volunteers and community members. Nicole Bryant and Fred Hennen were my anchors in Essex County. The New York State Office of Mental Health assured financial support as well as maintained faith in the vision of this effort. Sybil Goldman of the Georgetown University National Technical Assistance Center for Children's Mental Health conceived of this monograph and has been patient midwife in its birthing. Peter Lebenbaum and Cheryl Mitchell are my mentors and friends who present me with a model of total commitment to families. My husband, Joe Mahay, is always friend, teacher, and my primary support. I am particularly grateful to Velva Spriggs, Barbara Freisen, Barbara Huff, and Sybil Goldman for their thoughtful comments on this monograph.

Within the programs that I have developed and in my travels as a consultant, I have had the opportunity to listen to the stories of hundreds of families. I reserve my deepest appreciation for these families who have consistently shown an incredible generosity of spirit, despite the fact that they have often been so wounded by life circumstances and the service system.*

*There are times when I have used the word "parent" rather than "family member" in this monograph in order to differentiate the care-giver adults from youth in the family. I am aware that primary care givers can be individuals other than biological parents. Please read "parent" as anyone assuming a primary parental role.

I have recorded families' comments verbatim, and am most grateful to the eloquent voices that appear throughout this monograph. The following family members gave permission to have their words used: Diane Dier, Clare DuRoss, Pam Haran, James Karr, Marlene LaRock, Anne Mancini, Skye Mancini, Susan Peterson, Bill Quinlin, Laurie Rafferty, Karen Robillard, Rebecca Santillo, Helen Sherman, Nickii Sherman, Tracy Sherman, Mary Stockwell, Betsey Thomas-Train, Dagne Trembley, and Ginny Wood.

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Establishing the Vision

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Philosophical Foundation of Consumer Designed and Implemented Services

What could be simpler than creating services for people by asking them what they want and need? Yet inherent in that question is an enormous challenge to the established structure of service delivery. Basing services on what recipients say they want and need assumes that people know what they desire and know what is best for them. It confronts the very foundation of the classic professional/client relationship, which is built on the hierarchical assumption that the professional is the trained and skilled person whose job it is to advise and guide the client who needs help. The underlying assumption usually is that the professional really knows best what the client needs and what interventions will be most helpful.

> *In the 25 years that I received services for my child, nobody ever asked me what I wanted or needed.*

If we follow to its logical conclusion the principle that programs should be totally responsive to what the recipients say they want and need, we are then challenging the classic provider/recipient relationship. Allowing the consumer to be in charge requires a stance of respectful listening from the professional, and the formation of an equal partnership between the professional and the "client." A single mother of four daughters, three of whom had physical or emotional disabilities, said:

> *I told the social service aide that what I needed most was to have just a half hour to myself to take a walk and have some peace. [But] she wouldn't be with the children so I could do that because she said I always had to be there so I could learn parenting skills.*

Do we assume that she knew best what would be helpful to her? Another parent said:

> *I told the teacher that when my son gets out of control he needs to have someone sit close to him and hold him firmly and gently. She ignored me and continued to put him alone in "time out," even though that always made him worse.*

Do we believe that a parent who lives with a child 24 hours a day really knows that child best?

For families and professionals to work together as equal partners, we have to stop dividing the world into "helpers" and "helpees," as though these represented two different species. It is time to acknowledge that stressors like substance abuse, loss, illness, divorce, and mental illness occur in the lives of professionals as well as clients. They, too, can have children with emotional problems. We all are subject to the human condition and all have the same needs for comfort and hope when we are struggling.

The consumer movement in the mental health field has been growing steadily over the past few decades. Previously disenfranchised groups have been finding their voices and demanding more humane and meaningful treatment. The deinstitutionalization movement has forced society to respond to people with disabilities as full human beings. A philosophy of individualized, home- and community-based, client-centered, culturally competent services has evolved. However, making the subsequent paradigm

change is a lengthy and difficult process. Parents of children with emotional disabilities are one of the last groups to form a strong advocacy alliance because they have been reluctant to publicly identify themselves. They anticipate the usual reaction that there must be something wrong, "dysfunctional," with the family that has a member with mental illness. Only recently is the stigma of mental illness beginning to diminish, and even service providers are beginning to admit that they, too, have children with emotional problems.

Families of youth with serious emotional and behavioral disabilities consistently report that they have been subjected to *blame and shame* by the human services system. In an attitudinal survey done by the Southern Human Resources Consortium, 100 percent of families interviewed identified "inappropriate staff attitudes" towards them as a significant issue. Just as families wish not to be blamed, providers need to resist the tendency to become defensive when they feel criticized by consumers and their advocates. It should be clearly stated that the great majority of human service providers are motivated by concern and caring for the people with whom they work. In addition, service recipients often identify individual workers and particular agencies as having been extremely helpful, and even primarily responsible for their having achieved stability in their lives. But it is incontrovertible that the majority of families that have utilized the service system report feeling disempowered and blamed for their children's difficulties.

In my extensive interviews of families for Families First, they all have reported suffering in their attempts to get services which they felt they needed and, at one point or another, they all have felt denigrated by service providers. They often describe their search for help in the metaphors of battle.

The successful parent must learn the process—learn his or her rights—and then fight for them at every turn.

You cry when you go to a special education meeting, and you cry when you get home.

After a long history with services, I just feel pain and vulnerability. I find myself feeling ashamed when I walk through the door to try to get help.

In Harriet Johnson's studies of worker cognition about parents of children with mental and emotional disabilities, it emerges that workers with a psychodynamic or family-systems model are the most likely to hold parents responsible for their child's emotional problems (Johnson, Cournoyer, & Fisher, 1994). Most programs that train psychologists, social workers, and counselors teach theories and approaches that purport that children with serious emotional problems come from "dysfunctional families." It would seem to be impossible to consider working with families as equal partners if one's theoretical model is based on a pathological approach, assuming that the family is "sick."

A consumer-driven system takes an ecological approach to the etiology of serious emotional disturbance. It acknowledges that, despite advances in the social sciences, we still know very little about the development of human behavior. Some children can grow up in extremely deprived and punitive environments and emerge as well-functioning adults. These

youth have been designated as "invulnerable" or "resilient" children. We also know that the siblings of children with severe emotional problems are often emotionally healthy. We are continually learning that forms of mental illness are biochemically based and often have a genetic component. Rather than assume that all children with serious emotional or behavioral problems come from "dysfunctional" families, a more holistic approach is to look at the social, psycho-somatic, spiritual, and biological components of each family. Instead of attributing to families total responsibility for their problems, we need to acknowledge the factors that are beyond an individual's control such as genetic or biochemical causes, or the role of society in the creation of poverty and racism, or systems and policies which are destructive such as schools with pervasive violence or requirements that families must surrender custody of their children in order to get services.

Casting blame and shame on families is antithetical to the concept of creating a system of services in response to what families say they want and need. To work in partnership with families means having a strength-based frame of reference. It calls for approaching all families with the assumption that they are doing the best they can at that moment in time, given their inner resources as well as the outer resources that have been made available to them. Our human service system has maintained "problem-oriented records," and has all too often neglected to see and document the strengths that families have developed in the face of incredible stresses. It should be noted that having respect and compassion for family members and acknowledging the role of social injustice in their lives does not preclude acting responsibly to assure children's safety when they are at high risk of abuse.

Inherent in a family-designed system of care is the concept that services will be culturally competent and individualized and will stress the least restrictive, most normalized settings for children. When families are at the center of systems development, it follows that the professionals serving them need to become knowledgeable about and respectful of families' cultures and lifestyles. Extended families as well as others in the natural support system often are significant resources that can become an integral part of an individual's family plan. In addition, many families rely on their spirituality for solace and strength, and this, too, needs to be acknowledged and supported (Donner, 1994). Services have to be designed in accordance with each family's particular needs and strengths. Priority should always be given to "wrapping services around" each family rather than having to choose a "slot" in a categorical program. A basic assumption is that the best place for children to grow up is in a family setting in their own community; hence, it is the service provider's responsibility to utilize every resource to keep a child in the most normalized environment that is possible. In particular, no family should ever have to give up custody of their child in order to get services.

An apt metaphor for this new paradigm of service delivery is the image of the family in the driver's seat. In contrast, our customary way of doing business has been for the professional to be in the driver's seat, in control of the destination, route, and pace of the journey. The family is placed in the passenger seat, being taken along on the ride or even, at times, put in the back seat. If one begins with the fact that the family's life is at issue, then they have the right to be in charge. If they have the best knowledge

of their own needs, strengths, culture, and goals, then their place is behind the wheel—in control. The service provider belongs in the passenger seat. After working out the route with the driver, the provider can hold the map and act as a guide and support. The provider certainly brings experience and expertise that may help make the trip a safe and satisfying one.

If we believe that families know what they want and need, and that professionals are consultants hired by the families to help them reach their goals, then we are creating the blueprint for a family-designed system of services. If, in addition, we believe that people who have a disability or have lived with a person with a disability have gained invaluable experience, then the design for services will include consumers as service providers. Consumers have to be an integral part of the service delivery system in order to give constant feedback in the evolution of programs and to contribute their knowledge base to the program participants and non-consumer staff.

The only teacher who really understood my child was his seventh grade teacher. She had her own child with attention deficit disorder.

Teenagers need respite, too. We want a place to go to just rest, and not have to be therapized.

When I call the office I like to talk to Anne, because she's been through it just like me.

Ingredients of a Family-Centered System

A family-centered system means that families have *voice, ownership, and options* on every level:

Individual family—Family members are in control of interventions. They are included in all meetings about their child. They have primary input as to the agenda and who gets invited. They get to see all communications concerning them, especially evaluations and recommendations. They make certain that all interventions are responsive to their values and cultural identity.

Program—No programs are developed without significant consumer input. Forums are created for continual feedback from families as to whether or not programs are meeting their needs. Family members are well represented on program boards. Preference in hiring is given to consumers.

System—All planning committees have consumer representation. Support is given to family members to join together in advocacy groups to make their voices heard. Family members are given positions of power such as chairing groups or conducting presentations and trainings.

The philosophy that families truly need to be at the center of the development of a system of care led to the creation of Families First in Essex County, New York.

Families First in Essex County began without funding, without an established network, and without an infrastructure. We share this thought so that people will not be deterred by a lack of support or by what may seem to be impossible obstacles. Systems change is a lengthy and challenging process that takes patience, perseverance, and continual strategizing—and, ultimately, the support of a community of people. To implement a vision, the most important step is to have the courage to begin.

Implementing the Vision

The Setting

Essex County is an extremely rural county in the Adirondack Mountains in upstate New York. It is 1,900 square miles and has a population of 37,000. Isolation is a pervasive and painful fact of life for a good portion of the population. Winters are long and harsh, there is no public transportation system, there are very high rates of unemployment and poverty, resources are scarce, and opportunities for outside stimulation are limited. The county does not have an obstetrician, a child psychiatrist, or a child psychologist. At the time that Families First began, there were no intensive community-based services as alternatives to hospitalization in the county. Hearing of the plan to create a family-designed system of services, one provider said, "If you can do it here, you can do it anywhere."

An underlying assumption of the program is that all families have shared basic needs, regardless of differences in socio-economic status, culture, race, ethnicity, or sexual orientation. However, we also assumed that the service system that would evolve would need to be responsive to the needs and strengths of each community and sensitive to the cultural identity and uniqueness of each family. Although the rural nature of Essex County provided particular challenges and required specific program adaptations, the basic concepts central to the program are adaptable to any area and have begun to be replicated by others in suburban and urban areas as well as in other rural areas.

A Year of Planning

Initial Outreach and Funding

Although a long-time resident of Essex County in upstate New York, I had not been a part of the local service system when I conceived of this project. It was, therefore, necessary to make contact with the primary players and to assure their support of the concept of Families First. I was supported by the director of the Community Services Board who was, fortunately, not threatened by a "newcomer" with ambitious plans. With the director's encouragement, I met with people at the New York State Office of Mental Health (OMH) and was given funding through a CASSP grant for an initial planning year. In addition, I wrote and received two private foundation grants and received a small grant from the state Mental Health Association.

Our goal was to develop a shared vision among all the service providers and a sense of ownership and pride in creating an innovative, consumer-responsive system. I contacted all the pertinent groups in the county, including the Board of Supervisors, special educators, mental health clinicians, social service staff, and physicians and arranged to do presentations at their meetings. The county Mental Health Association agreed to become the sponsor of the project.

Family Interviews

Letters were written to all child-serving agencies, including schools, requesting that they contact families who had children with serious emotional and/or behavioral problems and get their permission to be interviewed.

We then followed up until those families were actually contacted and permission was given for interviews. In all, 24 families and/or individual parents were interviewed. Most interviews were done in the families' homes and took approximately two hours. A group of parents was interviewed together at a meeting of a chapter of the Alliance for the Mentally Ill. The interviews consisted of asking people to tell their "story," and then to answer three questions:

What has been most helpful to you?

What has not been helpful?

If you had a magic wand and could have any help you wanted, what kind of help would you like?

The interviews were tape recorded and written notes were taken as well. There was overwhelming congruity in families' responses. Parents expressed their pain at feeling rejected by the system, at not being able to get the support services that would be most helpful, and at feeling terribly isolated. They valued the support of respectful, caring providers who treated them humanely. Typical of their responses were:

All the energy that I put into fighting the system I could have used to help my family.

I felt like I was being subjected to blame and shame. I want the sense that I am being believed—that there is someone who understands the stresses that I live with.

I've never talked to another parent who had a child with problems like my child has.

I had to be my own advocate. I fought every step of the way.

I didn't give my son to social services. I just asked for help.

When Susan came to my house, I didn't feel that she was judging me.

Whenever I was in trouble, I knew that I could call Henry for help. He really cares about me.

Setting Up a Parent Planning Committee

We formed a Parent Planning Committee from among those who had been interviewed, choosing parents who were articulate about their needs and who indicated some awareness of systems issues beyond their own situation; an effort was made to get diverse representation. The core group that made a commitment to the process consisted of two fathers (one a single parent), and three mothers (one adoptive and two biological). Two of the parents were on public assistance; one parent was a therapist. One of the participants was the parent/director of the state Parent Support Network. The committee also had a "token" professional, the director of the county mental health clinic. Several additional parents attended one to three meetings before dropping out of the group.

The committee met for eight two-hour sessions. As we believed that parents were experts, we felt they should be paid for their time. They received $25.00 per session, plus mileage and child-care reimbursement. Their task was to take the recommendations from the interviews and design a system of services, making specific recommendations for implementation.

An unexpected bonus of this planning process was the extraordinary life changes that several of the committee members made as a result of participating in the committee. We made it very clear to those involved that the project did not have any money for services and that we were only funded for this planning year with no guarantee of future funding. A line item was written into the project's budget for a small amount of flexible dollars. As a result, we were able to provide a few concrete items, such as helping families get telephones. Feeling empowered by participating on the committee seemed to instill hope in the members.

The efficacy of creating an opportunity for families to have voice, ownership, and options is exemplified by the story of one of the Parent Planning Committee members. Sally is a single mother of four daughters who was living on public assistance. When I first interviewed her, she was living in a tiny, decrepit trailer at the end of a muddy, dirt road; her heater wasn't working and the water coming out of her faucet was brown and impossible to drink. She was a recovering substance abuser and had been psychiatrically hospitalized. During the family interview I recognized that she was, understandably, depressed and discouraged, but that she was also able to clearly articulate her needs and propose solutions. I invited her to be part of the planning committee.

Sally lived not too far from me so I drove her to meetings and we had a chance to talk in the car. Project money enabled her to have a telephone installed, and we talked occasionally on the phone. During the course of the planning year, Sally gained confidence and control of her life. She found a new and much better place to live, enrolled in the local community college, and began to take courses. She advocated successfully for her children in school, and decided that she no longer needed a preventive worker from social services. At an inspiring meeting with them, she read a list of the gains she had made, thanked the workers for their help, and terminated their services.

This story illustrates the healing power of having families at the center of system development. We sometimes assume that traditional therapy is the only effective intervention and forget that creating an opportunity for respectful, empowering, meaningful participation can be a life-altering experience.

Establishing an Interagency Task Force

Simultaneous to this parent-planning effort, we established a Families First Task Force consisting of representatives from all the child-and family-serving agencies in the county and of interested community members such as church leaders and retired social workers.

The Task Force met monthly for two hours. The agenda for each meeting consisted of introductions and updates from attendees, discussion of an issue such as prioritizing needs for families in the county, and a presentation

from a parent of a child with serious emotional problems. Listening to parents tell their stories in a public setting invariably moves people and helps them become empathic to families' struggles. In order to reduce the tendency of professionals to be defensive when parents told stories of frustration and anger at the system, most of the parents who were invited to present were from out of the county.

Three subcommittees of the Task Force were formed. One addressed the challenges of lack of transportation which the group felt to be a primary obstacle to service delivery. The second was to help the representative from the Housing Assistance Program implement a mandate to establish a five-year program to help families become financially independent. The third was a program and policy subcommittee. The latter consisted of the Commissioner of Social Services, the clinical director of the mental health center, the director of the Community Services Board, a special educator chosen to represent all the school districts, the Probation Department's diversion staff person, a Mental Health Association board representative, the Families First director, and seven parents. This distribution followed the recommendation of the Parent Planning Committee to have at least 50 percent of all advisory committees be family members. This subcommittee evolved into the steering committee for Families First and functioned in this capacity until Families First became incorporated and established a formal Board of Directors. A parent committee member said:

I feel vindicated by sitting on the committee. It used to be that I felt like a victim at meetings, with professionals having the goal of making me shape up. In this forum I'm taken seriously because I'm on an equal footing with the professionals.

Identifying Families' Priorities

The 24 families interviewed agreed almost completely about which services they felt would be most helpful. Significantly, the services requested by families tended to be support services that were less expensive and less intrusive than the programs for which professionals commonly advocate. When professionals design systems of care, those services that parents prioritize are usually not put in place until more traditional program components are established, or may not be offered in the range of services at all. It was humbling for me to realize that a decade earlier when I was participating in the design of a service system with professionals in another state, we hadn't thought to establish the services that parents were now telling us would be most helpful.

Suspecting that the needs expressed by families were fundamental to anyone dealing with severe stress, I conducted informal interviews with about a dozen people experiencing a variety of stresses such as serious physical illness, loss of a loved one, or divorce. When asked what they wished had been available to help them, they identified the exact same services chosen by the parents we interviewed.

The following clearly emerged as the highest priority needs of the 24 families interviewed:

Respite—Families said that they desperately needed a break. They couldn't utilize ordinary babysitters for their children with emotional or behavioral problems, and most did not have extended family members willing to help with child care. The majority had not had relief from the extraordinary demands of their children for many years. In one parent's words:

> *I was grief stricken when my child went into residential treatment. [But] our family was so exhausted that we felt that we didn't have an alternative. If only we could have had regular breaks, I know we could have kept our child at home.*

An Advocate—Families said that they felt alone in the process of confronting a confusing, fragmented system that frequently denigrated their perceptions. The services that they wanted meet the definition of what is usually thought of as a "case manager," but one who provides support and allows the family to lead:

> *I needed somebody that we could talk to, who would listen and guide us. Someone who was in our corner.*
>
> *We want someone to teach us how to maneuver through the system without disempowering us.*

Sometimes I just don't know what to do for my child and I need someone to help me make decisions.

Information and Referral—Families felt that they did not have easy access to information. They wanted to know the meaning of their children's diagnoses, to learn ways to cope with their child's behavior, and to understand the prognosis. Some parents talked about treasuring an informative book that had been given to them by a professional or another parent. They wished for a lending library of books, videos, and tapes about children with emotional disabilities. They also didn't know where to turn for help and wanted a place to go for referrals to good and appropriate services:

Nobody explained schizophrenia to me until a year after my son's first schizophrenic episode.

You drag your child around from person to person telling your story over and over again, baring your soul in order to prove that you need services.

I desperately wanted someone to teach me the system.

Parent and Sibling Support—Families said that they thought they were the only ones who were struggling to cope with the stresses of very challenging children. They felt that professionals hid behind the issue of "confidentiality" as an excuse for not introducing them to other parents. If parents were willing to give permission to share their names and phone numbers with other parents, then they concluded that confidentiality shouldn't be an issue.

I thought that I was the only one who was struggling with a difficult child like mine.

Parents don't get to meet each other. Confidentiality is used as the excuse to keep us apart. It would be so wonderful to talk to someone going through the same things that I am.

Parents also indicated that the brothers and sisters of children with serious emotional problems have a difficult time, and that they often got lost in the intervention process. Siblings want someone to recognize them and provide them with a chance to talk to others in the same situation:

My other sons were so embarrassed on the school bus.

A Family Center—Families wanted a central place where they could go for information, referral, and support. They did not feel that most formal agencies were welcoming or casual enough that they could call or drop in without an appointment. They also wanted a place where they could freely interact with other parents.

It would be so wonderful to have a place to go that is safe and comfortable.

There are 800 numbers for police and fire, but not for parents and kids who feel like they are going crazy.

A Community Friend—Parents expressed a strong desire for a "big brother/ big sister" type companion for their children with serious emotional and behavioral disabilities. They were concerned about the social isolation that their children experienced. If someone was able to form a special friendship and take their child out on a regular basis, it would provide stimulation and recreation for the child as well as respite time for the adults.

Parents said:

> *My other kids have a social life, but J. has no friends, no experiences to talk about at the dinner table.*
>
> *Being a single father, I want my girls to have a good female role model, like a big sister—someone they can talk to and do things with.*

Crisis Services—Many families' lives seemed fraught with crises. Even those who had a strong support system found that inevitably there were times when things seemed out of control and they needed help to cope. They didn't want to hospitalize their children and didn't know where to turn for help:

> *In a crisis we need support and practical suggestions about what to do, and then we need a follow-up call.*
>
> *I wished that someone could come into our house to help—maybe even a team, so that someone could be with my son's brothers and sisters.*

If only there was a safe, trained home where my child could go for a day or two when she gets violent and out of control. I know it would give us all a break, and then we'd have energy to work at it again.

Concrete Assistance—Families said that there were times when they needed some concrete help and nobody seemed to have the funds to provide it. There was no point in a professional recommending they get therapy if their car wasn't running and they couldn't get there or they couldn't afford the gas. Living without a telephone, especially in a rural area, creates incredible isolation. They said that at times the most helpful intervention would be receiving money for the crucial things they need (medications, a washing machine, a craft or recreational item that would keep their child occupied).

I needed to call the hospital in the middle of the night. I banged on the neighbor's door to use their phone, but they wouldn't let me in.

The electricity was shut off, the water pipes froze, and all the kids were sick. Then they wonder why I felt depressed.

Parent Planning Committee Recommendations

The outcome of the eight sessions held by the Parent Planning Committee was a list of 32 specific recommendations for Families First programs and policies. These have become the blueprint for the project. Over time, the concepts in the recommendations have been reinforced by new parents

as they have become involved in the program. The following are a sample of the challenging prescriptions that now form the foundation of Families First:

1. All committees, including the board and steering committee, need to have at least 50 percent parent representation.

2. Preference in hiring for all staff positions should be given to parents of children with special needs.

3. Parents should participate as trainers in the training of all staff and volunteers.

4. Parents should establish criteria for family-friendly agencies and award those that meet the criteria a Family-Friendly Seal of Approval.

5. Rather than simply assign staff to work with families, family members should be given the opportunity to interview staff members and decide whether or not they want to work with them. Participants and service providers should have an agreement for a trial period after which either party can decide to discontinue the contract. Scheduled periodic evaluations should be part of every agreement to verify that the match is successful and that the service suits both the provider and the family.

6. Families First needs to stress the importance of being sensitive to language that is respectful and inclusive of parents. Specifically:

> Families should be referred to as "**multi-stressed**," never "dysfunctional."

People using Families First services should be referred to as "**participants**" not "clients"; they should be called "**families**" not "cases."

The term "**advocate**" should be used rather than "case manager."

Families who decline to cooperate with services should be referred to as "**cautious**," not "resistant."

I am not resistant; I am cautious because of having been judged and blamed so many times in the past.

We are more likely to be open to working with someone who uses the more sensitive and accurate term. I can accept that my family is often multi-stressed, but we have never been dysfunctional. We have always functioned.

Families First in Essex County is Born

After a year of planning, our next step was to establish the system of care that the families had designed. Our dream was to create an agency to be named "Families First in Essex County," which would provide the array of services that families said they needed and wanted. The program would be a family-friendly system that would influence the way all services were delivered to families in the county. If the model was successful, we hoped to be able to disseminate it broadly.

Funding

Developing new social service programs almost always requires seeking funds from diverse sources. From its inception, Families First has been supported primarily by the New York State Office of Mental Health (OMH). Program implementation began with funds from OMH, several private foundations, and small grants from the Division for Youth and the Mental Health Association in New York State. During the planning year of the project, OMH submitted a research proposal to the Center for Mental Health Services, Department of Health and Human Services (DHHS), offering to compare Essex County with its family-designed system of care to a similar rural county that has a traditional, professionally designed system. This grant was received in the spring of the first year of Families First's operation and provided the basic funding for Families First for the next three years.

Other OMH funding streams provided additional sources of income that enabled the program to double its budget each year for three years, from

$33,000 for the planning year to $223,000 in the third year. Four Winds, a private psychiatric hospital, donated the time of a psychologist once a month and contributed towards the rent. Several private individuals also made donations. Families First formed its own board, 75 percent being family members of children with emotional disabilities, and became incorporated as Families First in Essex County, Inc., with 501(c)3 status. The board has begun to become involved in fundraising activities.

Establishing Working Committees

As it was essential for service providers and parents to have a sense of ownership of the project from the very beginning, small subcommittees of the Child and Family Task Force were established to hire staff, to find a site, and to oversee the initial purchase of equipment. The Families First Steering Committee assumed responsibility for program planning until the board was formed. All the committees had parent representation as well as representation from other county human service agencies.

Hiring Staff

Based on the recommendations of the original parent planning committee and the steering committee, the following positions were created and filled as funding was secured:

1. Director—3/5 time.*

2. Family Support Coordinator/Office Manager—The person to answer the phone, greet drop-ins, and cut through red-tape by assisting participants in maneuvering through the system.

*Naomi Tannen filled this position

We felt that it was essential for a parent to be hired for this position. (The woman who accepted the job has a bachelor's degree in psychology and is the mother of a child with Tourette's Syndrome and Attention Deficit Hyperactivity Disorder.)

3. Clinical Supervisor—A professional with a master's degree in social work (MSW) to supervise staff and be in charge of training. (A parent/social worker was originally hired for this position for 10 hours a week; however, she left the job and the director took over this role.)

4. Family Advocates—Staff who would provide home-based service to families, fulfilling the role usually defined as a "case manager."

5. Intensive Case Manager—A full-time OMH position that was designated to Families First, providing services to children with diagnoses of mental illness who were at risk of hospitalization.

6. Crisis Home Providers and In-Home Crisis Workers—Available as needed.

7. Home-Care Provider—A half-time position provided by OMH to our catchment area to provide support services to families as a way of helping to prevent out-of-home placement of youth.

In addition to the above positions, family members have been hired on a part-time basis depending on the funds available, the family member's time, and the job to be done. Positions such as host for special drop-in times have averaged two-to-four hours a week.The services of paid staff have been supplemented by volunteers and student interns.

Ads for staff positions specified that preference would be given to parents of children with special needs. Prospective staff were evaluated based on their training, professional experience, and experience as a family member of a child with emotional problems. The bottom-line requirement was that the person have a non-blaming attitude towards families and be warm and nonjudgmental. The original interviewers were parents and representatives from other agencies. Having parents as well as professionals interview prospective staff increased the likelihood of hiring people who were respectful of families. Once we had set up the center for Families First, parents, other staff, and the board president comprised the interview team. All were asked to consider, "Is this a person I would want to have come into my home to work with me?" The requirements of the job were, of course, taken into consideration. For example, intensive case managers had to have a master's degree or a bachelor's degree as well as significant experience. However, hosts of the drop-in times were chosen because they were parents of children with emotional or behavioral problems and had the social and communication skills to make other parents feel welcome. Families' reactions were:

I couldn't believe that the first person I talked to at Families First told me right away that she also had a child with problems. We talked on the phone together for almost an hour.

I came to Families First in my role of school psychologist to share information with them. But when I started to talk to Anne and realized that she had a child with emotional problems as I did, I ended up talking about myself and my son for two hours.

One of the first challenges that the personnel committee faced was the issue of whether a staff person with a bachelor's degree and parenting experience should receive the same salary as a MSW without parenting experience. We decided that if we truly valued the expertise gained from living with a child with special needs, we should make the salaries equal.

As we believe that families should have optimal choice, we make an effort to have a diverse staff. For example, a case manager position was divided between two people, a man and a woman, so that participants could choose the person with whom they would feel most comfortable. Utilizing part-time staff enables maximum diversity, as well as the ability to hire more family members.

Setting Up the Center

Following parents' recommendations, the Facilities Subcommittee rented a house located in Elizabethtown, the county seat. The house became our center and is in walking distance from other service providers such as mental health and social services. As mentioned previously, we were fortunate to have a grant through the state Office of Mental Health that covered start-up costs. The front room was designed to feel like a living room space with a couch, rocking chair, children's chair, and coffee table. The Family Support Coordinator works behind her desk, facing the entrance. One wall has floor-to-ceiling shelves for our resources—books, pamphlets, cassettes, and videos for parents to use and borrow. There is a small kitchen area as part of the front room, and coffee, tea, juice, and snacks are always available. Facing the front door, there is a dry-erase board that always has a welcoming message. Guests or groups who will be coming are welcomed by name each day. First impressions are crucial; being welcomed warmly by a staff person who is a parent of a child with special needs, who is totally accessible—not behind any barriers of glass or walls—transmits a strong message to families.

When you walk in here you feel safe. You don't have to get your guard up because you think someone is going to challenge you and make you feel bad about yourself as a person and a parent.

Being given a book that tells me about my child's problems and what I can do makes me feel respected.

What Does a Family-Friendly Agency Look Like?

The driving force behind Families First is the consumer. Families are not expected to accommodate to agencies' bureaucratic parameters, but rather the agency's reason for being is to accommodate to families. As a result, at Families First the daily schedule, hiring of staff, and utilization of resources are all organized to be responsive to families' needs and strengths. If a family is in crisis or has an immediate need, the staff is mobilized to be responsive to that need.

The atmosphere of Families First is frequently one of bustling activity, with a great deal of interchange between staff, participants, and any visitors to the office. Participants are treated more like guests in someone's home than like clients waiting their turn to see a professional. They are greeted warmly, offered a beverage, and introduced to anyone around. Private office space is available if anyone needs to talk confidentially. Much of the work is done in participants' homes and in community settings.

Participants may drop into the office to use the telephone, get information, ask a question, or borrow a book. They often become involved in helping with a project that is in progress such as getting a mailing out or planning a special event. Everyone in the office can be enlisted to respond to special requests such as "We're moving this week and need a pickup truck. Do you know anyone who could help us?" or "I have to take my child to the doctor tomorrow and I need a ride." Staff and other participants are seen, equally, as potential resources.

The following are the core services offered by Families First.

Drop-In Center and 800 Number

The office officially is open Monday through Friday from 9:00 a.m. to 3:00 p.m., however, someone is usually there at least until 5:00 p.m. It would be preferable to have even longer hours, but at this time we have not been able to staff the office after 3:00 p.m. on a regular basis. The 800 number is available at all times and messages are taken by an answering machine after hours. Special drop-in times are hosted by parents; these hours are advertised in our newsletters.

Information and Referral

The Parent Support Coordinator makes sure that we have as complete information as possible about resources. We have information about available services, admission criteria, cost, and necessary paperwork. In addition, we gather recommendations regarding family-friendly professionals. If we do not have the information available that someone requests, we try to get it for them. Subscribing to the local newspaper helps us keep informed about county activities and new services.

Resource Library

We have invested approximately $2,000 in our library. There are reference books, books for young people, books on parenting, books regarding specific diagnoses, and books on advocacy. Videos are popular among our parents; for example, our three copies of a video on living with a child who has attention deficit disorder are almost always in circulation. We maintain a file of articles pertaining to issues of emotional disturbance,

and we copy these for people to keep. Professionals as well as family members utilize the library. The Parent Support Coordinator follows up diligently on books that are out for a long time. We have lost very few.

Parent-to-Parent/Youth-to-Youth Support

Connecting parents with each other is a primary service that we offer. We see other participants as a significant source of assistance and think about making connections for every new referral. Our intake form asks if people are willing to have their phone numbers given to other families who may be in need of support. Family members, both youth and adults, often meet others at our office or at events that we sponsor, and maintain contact afterwards.

I wrote a letter to Nancy when she was in the psych hospital and told her that I knew what it was like because I had been there, too. I told her that when she got back to school she should call me. (17-year-old girl)

When Sam went to the hospital, I felt devastated and guilty. It helped so much to talk to another mother whose child had been away. She made me see that sometimes it was necessary, and that I wasn't a bad mother.

When I was out of control one night, the person I most wanted to call was Arlene from the Families First youth group. She talked to me for almost an hour until I calmed down. (13-year-old boy)

Home Visits

Newly referred families are offered the option of coming to the center or having a Family Advocate come to their home. While we provide ongoing home visits to families who are very stressed and/or who have a youth at risk of removal from the home, we also can make a home visit for an initial assessment and planning for any family that wishes one. A Family Advocate helps the family identify their needs and strengths, makes referrals for services, and informs the family about the ways that Families First might be of help. Not only are the services that are available to all participants described, but efforts are made to meet the immediate needs of the family.

Intensive Family Advocacy

The New York State Office of Mental Health has a program called Intensive Case Management. Families First received the contract for one intensive case manager (ICM) for the county. We chose to hire a man and a woman to share the position in order to give families maximum choice and to allow each person to work primarily in one area of the county. In order to be eligible for this program, youth need to have a DSM IV diagnosis and be at risk of removal from the home to restrictive placement, or be returning from hospitalization. Each ICM works with five families; in addition, they work with non- ICM families as a Family Advocate. They maintain very close contact with the families, providing interagency collaboration, individual work with the youth, and work with siblings and parents. The average length of service has been nine months; the longest, two years. The program has flexible dollars available.

Crisis Services

The Intensive Case Management program has an option to create crisis services using one fourth of the flexible service dollars for this purpose. Families active in the program as well as families on the waiting list can utilize these services.

Families First asked parent and youth participants to design the crisis program. They were asked, "What was helpful to you when you were in crisis? What services did you wish for?" The program they designed and that has been implemented has three major components:

1. Crisis homes where a child can stay up to 72 hours.

2. In-home crisis workers who are available 24 hours a day to come to families' homes to help de-escalate a crisis.

3. Training for parents in crisis management—strategies for crisis intervention and prevention.

Family Advocates work with families to design a safety/crisis plan as part of their initial planning process. The plan utilizes both professionals and a family's natural support system.

Families First has an agreement with a 24-hour hotline service. The ICMs train their staff regarding our philosophy and they are given information about the crisis program's resources. In addition, the ICMs give their home

numbers to the ICM families. As a result, the hotline only received three phone calls in 13 months. A parent notes:

> *When my son came home from the hospital, I was really nervous. Linda [our Intensive Case Manager] had me call her every evening for two weeks just to let her know how I was doing.*

Respite

Families First has not had specific funding for a respite program. Knowing that respite is a very high priority need for families, we have utilized existing resources to help families have planned respite. We help families explore the options available through their natural support systems and utilize all of our resources. For example, if a family has several children, we help them strategize about relatives or friends who might each take one child for a day and/or night. We may use flexible family-support dollars to pay for respite, or for a small stipend for child care, or for dinner in a restaurant. Our Home-Care Provider might take the children out for an afternoon in order to provide respite for the mother.

If a youth in the ICM program is in a very vulnerable state and remaining in the home appears to be tenuous, we have used crisis homes in a planned way as crisis prevention/respite for the youth and parents.

Families First also wrote letters to all the bed and breakfasts, inns, and hotels in the county asking if, at a time when a room would likely be unused, they would be willing to offer a free night's stay to parents of

children with special needs. Fourteen places answered that they would be glad to do that. Parents were delighted:

> *I stayed at a beautiful bed and breakfast. It was the first time I had been away from my children overnight. I slept in a canopied bed and felt like a princess!*

Community Friends

Matching participants with a "special friend" often has a very significant impact on the participant's life. Although community friends have primarily been assigned to youth, we have also created matches for adults. Volunteers and interns have served as community friends. They receive training and ongoing support. Community friends are asked to make a commitment for a year, with an initial three-month trial period to see if the match is a good one. This special relationship can sustain youth through times of stress, help them move from isolation, and develop their interests and social skills.

> *When I arrive at Tom's house, he has a list of all the things he wants us to do together that day. We usually manage to do them all!*

> *Sarah asked if she could call me grandma. I look forward to being with her every week. We sew and cook and do all kinds of projects. I just love that child!*

Advocacy

Families frequently request assistance in maneuvering through the complex, confusing system of services or in acquiring the services they feel they need. Staff members and other parents are available to give information and provide support. This might mean attending an Individualized Education Plan meeting at a school, accompanying the family to a court hearing or social services case review meeting, or helping a family contact a lawyer.

Advocacy has sometimes meant supporting families in their efforts to bring about change in the system. Staff members and participants have been allies in advocating for the restoration of funds for needed services or in changing institutional policies to be responsive to families' needs:

> *You stuck by us for the 14 months that we tried to regain custody of our child.*
>
> *I felt like I could really make a difference when we arranged that meeting with the hospital people to tell them how hard their admission process had been for me.*
>
> *It gave me courage to speak up when Priscilla was with me at the school meeting.*

Social and Recreational Events

When Families First began, one of our initial efforts was to establish support groups around the county. Families told us that they wanted family-led

groups, so we located teams of two parents in each area and provided training for them. The group meetings were well publicized. To everyone's disappointment, hardly anyone showed up. Most groups had one or two people attend besides the leaders. We said that even two people made a group and we wouldn't give up. The groups continued to be offered for more than a year, with no change in attendance. One day, someone jokingly pointed out that we never had trouble getting lots of people to attend the social events that we sponsored. Aha! The message was clear. If people chose to leave their homes and travel long distances, even in very bad weather, to come to a party, then the parties must be fulfilling a need. We asked more questions and listened to families. They told us that they were reluctant to go out after a long, hard day to listen to other people's sad stories. In our rural area, families often had history with other families in the group and they didn't want to reveal their personal feelings to those people they already knew. Because their lives were often drab, however, they were willing to go out to an occasion that their whole family could attend and that felt like fun. The conclusion was clear—more parties!

Families First has worked with parent and youth advisory committees to plan events such as a cider-pressing party at a board member's farm, a party to celebrate Families First's birthday, a Thanksgiving dinner for families who didn't have extended family to celebrate with or the resources to buy and prepare the food, and other holiday parties. In the summertime, we had two picnic/barbecues at state parks and took 40 parents and young people to a water-slide park. We never had more than five or six people attend a support group, but the 1994 holiday party was attended by 94 people.

I got to wear a Santa costume and give out gifts at the party. We all set up and cleaned up together. I really felt like this was my family.

At the party, I met a woman who had been in foster care with me when I was a child. We felt like sisters. We talked and talked and made plans to get together again.

At the picnic, I met a father whose son was on Ritalin like my son. We talked about what it was like and some of the troubles our kids had gotten into.

At these social events, participants make their own connections. They talk together, provide support to each other, and frequently exchange phone numbers and addresses so that they can maintain contact afterwards. Staff, board members, and their children have an opportunity to share the event with participants and their families.

It is important to note that other agencies have had very successful support groups, many of which have been ongoing for long periods of time. The lesson to be learned here is that a program has to be responsive to the needs of its participants as the program develops.

Everyone needs support. Not everyone needs support groups.

Flexible Dollars

It is impossible to have a system that is responsive to families' needs and strengths without having discretionary money. Such a lack results in situations such as:

> *There was money to send my child away for a year, but no money to get me a telephone or to hire someone to give me a break once in a while!*

> *I can't think about going for therapy when my pipes are frozen, they're going to shut off my electricity, and I don't have money to pay for car insurance.*

> *The thing that makes me happiest is drawing. I just wish so much that I could have art lessons.*

A critical lesson for any administrator creating an agency's budget is to include a line item for flexible dollars. If the constraints of the agency don't allow this flexibility, then lobbying for change is essential. In the meantime, the agency should approach private sources to get flexible dollars. A relatively small amount of money can go a long way towards meeting families' critical needs.

Maximizing the effectiveness of flexible dollars is not an easy matter, and educational institutions do not teach people how to do this. At Families First, we are constantly learning from experience how to utilize our discretionary funds for families in ways that are respectful of family values and deliver the most benefit.

Naomi said we had 50 dollars to spend for Christmas presents for the family. She brought us some catalogs and had a family meeting with us. Everyone had lots of ideas, but we wanted to buy things the whole family would enjoy. We had to listen to each other before we decided. Then we all went to the store to buy the things we had picked out.

I was going to lose my job because I couldn't pay my car insurance and there was no way to get to work. Families First loaned me the money to pay the insurance. What a relief!

My daughter was threatening suicide and I was so scared that she would overdose on pills. Families First gave me the money to buy a locked box in which I could put away all the medications.

When we worked on our plan, we decided to put an ad in the paper for someone to come into my house every week to help with the kids. I have muscular dystrophy and sometimes I get so tired and cranky. It really helps to get a break.

Sometimes it's hard to make the choice between acquiring material objects and providing services for families. It's also hard to set limits on families who are constantly in financial crisis. A committee of parents to review requests for assistance can be helpful, or staff meeting time (with parent/staff present) can be used to make these decisions. Of course, it is essential to plan with families so that their priorities guide the decisions and so that alternatives for getting the money can be explored.

Youth Activities

When Families First began, we were totally committed to working in a partnership with parents and other adult care givers in the family. At the time, our consciousness was not raised as to the need to be equally inclusive of the youth participants. Just as it is common sense to develop a program based on what parents say they want and need, it also should be self-evident that a program should be responsive to what young people themselves say they want and need.

Families First has worked to overcome the original omission of full youth participation. In its first year, Families First established a Youth Advisory Committee. This was a multi-aged group which included young people from the ages of 11 to 19. We have since divided the youth into a younger group of 11 to 14-year-olds and a high school group. The youth groups have been responsible for planning activities and have sponsored both large- and small-group events for entire families or for youth only. Sometimes the young people decide to include siblings; sometimes they invite their friends. A staff member has assumed the role of Youth Coordinator as part

of his job, and he does at least one youth activity a week. We also have arranged special activities to meet individual needs such as organizing a bi-monthly art class and a writing class, and we are planning a summer day camp. Staff will be assisted by parents and high-school-aged participants.

The teens in the advisory group asked to have a teen girls support group, which has now been established. We have found that our youth participants can offer support to each other in very effective ways, just as the adults can.

> *One night I really lost control. My mother said I could call my counselor or anyone else from Families First, but I called Nicky (another youth from the advisory committee) and she talked to me on the phone for a long time and calmed me down.*

Just as we are committed to including parents in trainings, we now include youth, too, whenever possible. Youth have presented at national conferences with staff members. When individualized planning meetings are held, youth are always included. It is essential to hear their needs, recognize their strengths, and have them participate in and "own" the plan that emerges. One youth said:

> *My mother got to go on respite, but I told the Advisory Committee that I thought that kids need respite too. We need a place to get away and not be counseled—just a chance to rest, take a walk, think. I was so glad that they set it up. Now I can go to stay with Winky and Sandy when I just need a break. It helps to keep me going.*

Individualized Family Planning Meetings

Any effective intervention on behalf of families in stress requires a collaborative effort by the entire support system so that services are not fragmented or duplicated and so that everyone can work together towards shared goals.

Families First offers all its participants the option of having a planning meeting facilitated by a Families First staff person or by the parents themselves, if they prefer. These meetings are an essential part of the Intensive Case Management program, but are also available to participants for whom we cannot offer ongoing intensive family advocacy services.

Families take the leadership in every step of the process. The staff person meets with the family to plan the meeting. The family decides who shall be invited. They are encouraged to invite all the providers who are working with them such as therapists, social workers, teachers, school psychologists, probation officers, as well as members of their natural support system who they perceive to be helpful (relatives, neighbors, friends, babysitters). A time and date that is convenient for the family is set. The family and staff member discuss who shall do the inviting to the meeting. Usually this task is shared between the parents and the staff, with the parents choosing those they would like to contact. The child is always invited to the meeting, and may also choose to bring an advocate, such as a close friend.

Prior to the meeting, the staff facilitator meets with the family to plan the agenda and discuss the family's goals for the meeting. Sometimes the parents choose to facilitate the meeting themselves. Meetings are

held at a time that is convenient for the family and in a place where they will feel comfortable—in the Families First office, at school, or in their home. Meetings are scheduled for one and a half hours. Prior to the meeting, newsprint sheets are posted on the wall with the following headings:

* Family
* Support System
* Strengths
* Issues
* Plan

During the meeting, the facilitator takes notes on the newsprint sheets and, afterwards, the notes are written up as minutes and mailed to the attendees. This serves as a reminder of the meeting's content and of the commitments that members of the group have made. The discussion always emphasizes the role of the natural support system and the family's strengths.

Towards the end of the meeting, the families are asked if they would like to identify a smaller group of people to serve as a support circle which could meet again when the family feels the need for further support. Families usually identify a combination of professional people whom they trust and members of their natural support system. The larger group can also meet regularly, in some cases monthly, or as needed.

Newsletter

A newsletter written by family members provides a vehicle for information sharing as well as an effective means of giving participants increased ownership of the program. Families First's newsletters have included profiles

of staff, families writing their "stories," reports on events and trainings sponsored by Families First, survival tips for parents, a "For Sale, Wanted, and Trade" column, poems by youth, and a column for parents offering or seeking support. The High School Advisory Committee is currently planning to produce its own newsletter for youth.

Informational Meetings and Trainings

Families First holds monthly informational meetings for families and providers on topics that are chosen by family members. Topics have ranged from "Living with a Child with Attention Deficit Disorder" to "Sharing Ideas for Cutting Down Your Food and Fuel Budget." After an evening for adoptive parents, the group decided to meet again for several sessions. Speakers on school avoidance and sexual abuse attracted many providers and parents.

Both parents and youth participate in trainings for staff, volunteers, and crisis workers. It is crucial that prospective workers hear from participants and have an opportunity to ask them questions. Crisis home providers and in-home workers are also required to spend time in a participant family's home. Participants are welcome to attend trainings that are held for Families First staff members. When people from other areas come to Families First for training, participants are paid for their time if they agree to have the guests observe a home visit or individualized planning meeting.

> *I was glad to tell my story to those people from Canada, and have them visit in my house. It gave me a feeling that I was helping other families get family-friendly treatment.*

Concrete Services

A system that purports to offer family-support services cannot ignore participants' needs for practical assistance. As with other services, it is not necessary to assume that professionals have to meet these needs. Families First refers people to community resources and helps connect families with each other. Staff, participants, board members and community people all share in efforts to meet people's needs for concrete help. When families are multi-stressed, having their practical needs met enables them to devote more of their energy to dealing with their children's needs.

I felt like I needed a husband—not one to live with, but someone to fix my car and teach my son to shave. Families First hired a person to come and do those things for me and to teach me how to do them for myself.

My car needed new brakes. I couldn't go to visit my daughter in the hospital without a car. Families First loaned me the money to get the car fixed.

We made a great deal. I got the money I needed to pay my bill so I wouldn't get in trouble, and I built some shelves for the office and fixed a broken chair for Families First.

Principles of a Family-Friendly Service System

Creating Community

Now that Families First has been operating for over two years, it has become clear that the most significant and "therapeutic" role that we play is to offer participants a sense of community. Families First has become like an extended family to many participants. Richard Almond in *The Healing Community* refers to "healing charisma" (Almond, 1974). Through shared rituals, responsiveness, and accountability, families gain a sense of identity with an agency and come to believe that being a part of the organization will improve their quality of life.

> *I didn't have a family, but now I've got one. Families First is my family.*
>
> *It's not like you come here and people have to solve your problems for you. But there's an atmosphere where you are able to use what you have to the best of your ability. A little bit of support goes a long way.*
>
> *People here truly believe that parents are not to blame.*

Offering unconditional care, availability, nurturing, as well as specific services, leads people to gain confidence and the courage to cope with their challenges. Feeling that they are a part of something larger than themselves gives their lives meaning. Increasingly, families at Families First offer to help us and other families in a myriad of ways.

My children have outgrown these clothes. Can you find someone who can use them?

We've cut down an extra Christmas tree. We'd be happy to deliver it to another family.

You've helped our family so much. I'd be glad to build those shelves that you need.

Support and Hope

Lack of social support has been shown to be as great a health risk factor as smoking, lack of exercise, and high cholesterol (Pilisuk, 1986). Families who have children with serious emotional problems have the least social support of all families who have children with special needs. The ensuing feeling of isolation makes families feel desperate and unable to cope.

Dr. Rick Snyder at the University of Kansas has done research showing the vital role of hope in creating better outcomes for people under physical and emotional stress (Snyder et al., 1991). A family-friendly service system finds concrete ways to provide support and instill hope in its participants. Continually reinforcing strengths, creating awareness of small changes, and communicating a belief that things can get better need to be integral to the tone of a program.

I don't think I would be alive today, if Families First hadn't been there for me after my first suicide attempt. (15-year-old girl)

As soon as I heard the bad news, I came right over to the office and spent the whole day there. Everyone there cares so much about me.

Families as Service Designers

In a family-friendly system, all program decisions are made in response to what families say they want and need. Therefore, no policies should be set or activities planned without turning to the recipients as primary consultants; this holds true for decisions both large and small. For example, when a new staff person at Families First was hired to work in a more remote part of the county, the staff didn't decide how her time would be utilized. Instead, a meeting was held in that area to ask people how they would like her to use her time. An invitation to the meeting was sent to all those families who had been involved, even peripherally, with Families First, and an article about the upcoming meeting was placed in the local paper. It was crucial for the Families First staff person to go into that initial meeting with a completely open mind, ready to listen well to the participants. This group requested that the staff person work with individual families, and that there be a monthly informational meeting with a speaker and a time for informal socializing and mutual support. A smaller group of parents volunteered to work with the staff member as an ongoing planning group, so that each event would be designed by participants.

When social events are planned, committees of parents decide on the details, decorate the hall, and help clean up afterwards. For this year's holiday party, we gave money to one parent to purchase the decorations; another parent brought in a pinata; and still another family brought a tree.

When grants are written, participants should provide input at the outset and should be part of any implementation group if the grant is received. Including families in all decision making regarding any program development should be an integral part of an agency's ethos.

> *The trouble with most professionals is that they have all of the answers and none of the questions.*

If families are truly at the center of systems development, we have to continually ask the questions and listen to the answers!

Blurring the Boundaries

Human services students are usually taught that it is very important not to blur the boundaries between clients and professionals. In traditional therapy this may be true; and certainly boundaries that protect program recipients, such as not engaging in any activities that abuse the power relationship, need to be faithfully adhered to at all times. However, in an organization in which program recipients and providers work together in a true partnership, boundaries are inevitably blurred. For example, since Families First gives preference to parents in hiring, many staff members are also program participants. Agency events are attended by participants,

staff, and board members—all with their families. Most of the staff give families their home phone numbers so that they can be available in times of need. It is not unusual to exchange gifts or help one another out. People do not refrain from expressing affection in the form of hugs or an arm on a shoulder when this is appropriate. Participants sometimes visit staff homes for a planned activity or if the staff person is offering respite to a child. To fulfill the Parent Planning Committee's recommendation that the motto of Families First be "People Helping People," we need to think more in terms of a community than an office.

Blurring the boundaries requires a great deal of thoughtfulness and responsibility. But one should remember that the traditional hierarchical relationship by no means precludes exploitation, and, in some instances, may even enhance its likelihood.

Family Members as Providers

Most people can remember a time when they were under stress and sought, or wished for, contact with others who had the same experience. This can be true for life challenges such as a chronic illness, divorce, being a step-parent, or having experienced violence or a natural disaster. One feels that someone else who has been through the same experience can offer true empathy, "I know what it's like because I've been there."

Family members of children with serious emotional disturbance, as well as the youth themselves, often express a yearning to talk with others who have shared their experience.

When I met with other parents, we were able to laugh together about some of the hardest times. We all had stories about taking our kids to the dentist and being so embarrassed in the waiting room while our children could be heard bellowing in the next room, or having our neighbors and relatives stare at us as if we were monster parents!

How could a therapist really understand what we were living through if he or she had never lived with a child like mine 24 hours a day?

It is essential that a family-centered system of care hire as many staff who are caregivers of children with emotional problems as possible. At Families First, five of eight staff are parents. This ratio assures that participants will have contact with staff who can understand their challenges from first-hand experience. The parents on staff serve as consultants to the rest of the staff whenever issues about programs or specific services arise.

It is crucial to pay parents who offer services. Some organizations have realized the importance of having consumer representation on boards and committees, but have assumed that family members will volunteer their time. Professionals almost always attend meetings on work time; it is not respectful to expect family members to give their time and expertise without being remunerated. If we truly value their contributions, we should make certain that they are reimbursed for time, travel, and child care. It is also important to be sensitive to parents' schedules and to try to hold meetings at times that they can manage to attend.

Families First has a budget category for "family support" that we utilize to pay parents when they participate in training of staff, serve as committee members, or give us time as consultants. For example, the staff had noted that one of our participants was unusually skilled at parenting, despite the fact that she had grown up in an abusive home. We wanted to know how she thought she had managed to gain the parenting skills, never having had any good modeling. She came in for a two-hour interview and was paid for her time.

It should also be noted that having family members play the dual roles of recipient and provider of services presents many challenges. Staff who are living with children with diagnoses of mental illness inevitably go through times of crisis. It is difficult to be available to other parents when one is struggling with one's own problems, to inspire hope when one may be feeling discouraged. It is also difficult to relate to staff as peers when they are involved with your family as a provider. We have found that some parents are more comfortable than others in dealing with these complex roles. Several of our parent/staff members have had to leave their jobs with us when their children were under severe stress. We have made a commitment to talk about these issues at length and in depth with the parents. As a result, we have been able to work out flexible, individualized plans with parent/staff members so that they can take a break for a while from their staff position and/or assume a different, less intense work role if they feel that it is necessary. (See Appendix: *A Letter to Parents Regarding Working with Families First.*)

People Helping People

When the original Parent Planning Committee that designed Families First made the recommendation that the program's motto be "People Helping People," they felt the phrase would emphasize that there was not a hierarchy of helpers defined by status, or the division of "helpers" and "helpees." They recognized that community volunteers, other parents, or youth might sometimes offer the primary therapeutic intervention for a family. Being able to give services as well as to receive assistance gives families the opportunity to have more meaning in their lives and to increase self-esteem. Families First's intake form not only asks what a family needs, but also what they might like to contribute.

A good example of the pleasure gained from a mutually beneficial sharing is the story of a participant family we matched with an elderly volunteer. The participant is a single father with two children, both suffering from post traumatic stress syndrome. They are newcomers to our area and are disengaged from their extended family. The 83-year-old volunteer had recently been through a severe depression caused by her sense of having lost her usefulness in life. At Christmas time, the participant family brought a tree to the home of their new "community friend," and the friend cooked them a holiday dinner.

> *Volunteer: "I had the best Christmas I've had in years. They brought me a huge tree and we decorated it together. We had such a good time; it was like a wonderful family."*

Participant: "Sarah made a great dinner for us. I hugged her and told her that she was like a mother to me, and a grandmother to my children. We all felt safe and warm in her house."

Another parent/provider, a single mother, works part-time in our office providing support to other parents. She doesn't have a car. A mother who also works part-time for Families First co-hosting a family drop-in time with her husband, drives the single mother to town each week to do her shopping and laundry. The examples of "matches" that Families First has made among participants and between participants and community volunteers are innumerable.

The incidents of spontaneous generosity are also legion. The following may provide a taste of the daily occurrences that give the organization its flavor:

* A mother of a child who has just been hospitalized is introduced to a mother who has been through that experience recently.

* A teenager who used to be in placement corresponds with a teen currently in placement and offers to provide support when she returns to the community.

* A participant brings in baby clothes for another participant

* A family who received a free psychological evaluation wants to "give back" to Families First by providing holiday gifts to help another family.

When a system is truly responsive to families' needs and strengths, it inevitably leads to mutual giving and receiving.

Creative Use of Existing Resources

In our country, it is a fact of life that we do not have sufficient funding to provide adequate social services for all families. Some areas are more resource-poor than others. Inner cities and very rural areas probably suffer the most, because each has unique stresses that require substantial and innovative services. While it is essential to lobby for the funds for preventive as well as treatment programs and cost effective home and community-based services, we should not use the lack of funds as an excuse to avoid delivering services to families. The challenge is to utilize existing resources in the most creative, culturally responsive ways possible. This calls for utilizing the private sector, service organizations, and volunteers. It means working with other providers to combine resources and share funding. Also, it may mean bartering with other organizations to exchange the resources that each has.

When confronted by a participant's need for which we have no funding, we see it as a challenge, and the staff and family brainstorm together. This action models problem-solving techniques and instills hope in people. Of course, all needs can't be met, but there is solace in just knowing that a community of supportive people is working together to search for solutions.

Meaningful Record Keeping

A family-friendly organization should maintain the goal of requiring minimum paper work, having only forms that are useful, and supplying meaningful information. On any form that elicits problems, there should also be a place to list strengths. The language that is used on forms should be clear and simple, but not condescending. The forms should reflect the program's philosophy. (See sample forms in Appendix.)

Our crisis program offers youth the option of going into a short-term (up to 72 hours) crisis home. We developed a Comfort Form that parents and children fill out and is given to the crisis home prior to the child's arrival. This form asks families about bedtime and other routines that their children find comforting—a light on at night? a special toy? food preferences? It also asks parents to list interventions that they have found helpful with their children. A form like this shows respect for parents' knowledge about their own child and helps make the crisis-home experience more positive.

Participants receive a very wide range of services, depending on their needs and desires. Some people just want to borrow a book on behavior management from our resource library. Others want intensive home visiting and advocacy. We do not maintain files for families who use minimal services (for example, those who call the 800 number sporadically to get support, drop in occasionally, or attend informational meetings). Files are kept for families who are in our Intensive Case Management program or who have requested a home-based Family Advocate. All records pertaining to a family are made available to them, and we inform other providers of this policy. All plans reflect families' wishes and are made in collaboration with families.

No Waiting List

When Families First began, we made a commitment to not having a waiting list. People said it was impossible to avoid. As predicted, we have had continually increasing referrals and referrals of greater severity, but we have never said to a single family, "Sorry, you'll have to go on a waiting list; we can't do anything for you now." The solution has been the policy that "We can't do everything for everyone, but we can do something for everyone."

Anyone who contacts Families First is invited to drop in to the office and talk to our Parent Support Coordinator. The 800 number is available to all families in the county. Anyone can utilize the resource library, borrow a book or video, or take home an article to keep. Monthly informational meetings about a topic that families have expressed an interest in are open to everyone. Everyone also is welcome to attend social events. Family members can be matched up with another participant for support. Youth can participate in our youth activities. Although we do not have the staff to provide ongoing intensive home-based services to everyone, we offer at least one home visit to hear a family's story and to help to make a plan utilizing whatever resources exist. We also offer to facilitate a planning meeting that includes everyone involved with the family.

In keeping with Families First's commitment to be "family friendly," people who call or drop in who do not have children with emotional problems are still greeted warmly and are given referrals to appropriate services.

Coming over to Families First has kept me sane.

I feel safe when I'm here.

It was so good to be able to drop in almost every day while I was on the waiting list to see someone at Mental Health.

The first time I came to Families First I met another parent who was there borrowing a book. We got to talking and I realized that I wasn't alone.

Agencies that are forced to maintain waiting lists for those wanting to receive particular services such as outpatient therapy can still offer support to people while they are waiting. There are agencies that have asked their participants for ideas to cope with waiting lists. They have created supportive options such as holding an open house once a week where those waiting can talk to a therapist, calling a person regularly while they are on the waiting list to assure them that they have not been forgotten, and giving people telephone numbers of other families for support. These approaches to easing the waiting-list problem were adopted from Kinark Child and Family Services in Peterborough, Ontario.

Making referrals to other agencies where families can get some immediate assistance is also helpful. There is nothing more frustrating and painful for a family who is in stress than to be told that they simply have to wait for a long time to get help. By not being available, the system teaches

families that the only way to get help is to go into crisis. Those systems that have not found ways to be responsive to families are usually very crisis-oriented and spend a great deal of time and energy responding to emergencies, rather than delivering planned and preventive services.

Do Unto Staff As You Would Have Them Do Unto Participants

It is impossible to create a truly family-friendly agency unless staff policies and attitudes reflect a coherent philosophy. If participants are to be empowered and respected and if they are to have flexible, individualized programs, then staff also deserve the same treatment. An informal welcoming system that is open to listening requires a non-hierarchical work environment. Seeing strengths, encouraging people to fulfill their potential, and responding to needs with a generosity of spirit is as important for staff as it is for consumers.

> *I want to thank the rest of the staff for coming through for me when I was going through such a tough time. I appreciated the flexible work schedule, John stopping off on his way home from work, and everyone's support.*

In order to create a team spirit and a shared vision, time needs to be set aside for meetings. It is necessary to establish forums for sharing successes and concerns, thinking together creatively to help particular families, evaluating services, and reaffirming the program's mission. Families First has a two-hour weekly staff meeting, individual supervision, and a quarterly all-day retreat that is held in someone's home. Of course, parent/staff are always at these meetings so that maintaining a family focus is assured.

Staff that work in a communal atmosphere are able to cooperate easily. At Families First, staff function as a team. Even though a particular person is designated as the primary advocate for a family, other staff members become involved with the family. If their advocate isn't available, participants usually feel very comfortable talking to anyone who is in the office. Referrals for support are frequently made to other participants or volunteers, and these people are considered to be as valuable as staff. Staff never use possessive language referring to a family as "my family." Good communication is essential to this kind of team work.

All advertisements for new staff state that "preference is given to family members of children with emotional or behavioral problems." Many positions are part time, ranging from parent drop-in facilitators who work only two hours a week to a 35-hour-a week parent-support coordinator.

Evaluation

Evaluation has to be an integral part of the system in order to sustain a vital organization that is optimally responsive to families. Just as individual family plans have to be open to change in response to changing circumstances, systems and programs have to build in opportunities for feedback so that they can be appropriately responsive. "How are we doing?" needs to be asked in a myriad of ways for every aspect of the system. It is easy to become complacent with a program and to continue doing what has been done before rather than to assume that one is always learning and that a system should be constantly evolving.

JoAnne always asks me "Is this helping?" If it isn't, we think together to find another way to do it.

Naomi asked us if our teen girl's support group was meeting our needs, if we wanted to continue meeting, or if we wanted to do something differently at the meetings—like maybe do activities or have guests come instead of mainly talking.

Some mechanisms that Families First has used for evaluation are:

* Mailing a questionnaire to all participants with a self-addressed, stamped return envelope, asking about usefulness of the program.

* Setting times for evaluation of any "matches" between participants and providers, usually after three months.

* Arranging frequent feedback sessions to which participants are invited.

* Including feedback from participants in staff evaluations.

Availability and Responsiveness

A family-friendly system does not have arbitrary periods of intervention for all families. If services are individualized and flexible, the length of service needs to be negotiated for each family, depending on its needs

and strengths and on the circumstances of family members' lives. An apt model is one of the family physician. A family doctor does not close a patient's case after an illness. There is the assumption that the person will need care again at some time in the future and that the doctor will be available to the patient as needed. Human service providers should maintain the same attitude; families who have a child with serious emotional disturbance will likely need support at various times in the child's life and should be able to return to a trusted provider for assistance.

The more available and responsive a system is, the less likely it is that it will be crisis-oriented. Families will not get the message that they need to have a crisis in order to get services and preventive work can be done. The end of a period of service intervention should not be seen as "termination" but rather as "transition". The transition can be to other services or can offer the option of some ongoing support, if needed.

Interagency Collaboration

Ralph Waldo Emerson said, "There is no limit to what can be accomplished as long as it doesn't matter who gets the credit." There appears to be a natural tendency for people to protect their turf. Especially in times of scarce resources, people tend to hold onto whatever they manage to get and may be reluctant to share it. To counteract these tendencies, we need to have the wisdom to understand that unless providers share resources and information and work collaboratively, services will be fragmented and possibly duplicated.

I didn't know where to turn. Everyone was giving me different advice. There were literally 20 different professionals working with our family and none of them ever talked to each other.

If only I could give to my child the energy that I put into fighting the system, our lives would be so much easier!

Using a medical analogy, it is difficult to imagine undergoing an operation if the various specialists have not shared information and worked as a team. Yet in human services, this lack of sharing is a common occurrence. Collaboration takes time and is an activity that often is not reimbursable. However, it is inconceivable to imagine that we can adequately meet the needs of a multi-stressed family without communicating and coordinating with all the players involved with that family.

Achieving a collaborative spirit among providers calls forth all the skills that a person would use in an effort to directly assist a family. Providers who feel disempowered are likely to be as cautious and obstructionist as disempowered families who lack trust in the system. Anyone taking on the task of being a family advocate and trying to coordinate services needs to understand and be able to access the strengths of other providers. They need to have infinite patience, be willing to strategize when efforts to elicit cooperation fail, be responsive to others' needs, and be completely reliable in fulfilling commitments.

The challenge of achieving collaboration is increased when one is committed to the concept of families being at the center of systems development and in charge of their own lives. The concept of a parent/professional partnership is still a new paradigm, and many traditional providers are reluctant to surrender control to families. As discussed previously, they have been trained to see families as "dysfunctional" and, therefore, cannot conceive of them as "experts" in regard to their own lives and their children. Being asked to sit at the table with clients and to interact as peers can be very threatening to many professionals. This is true both at meetings concerning individual families and at committee meetings dealing with systems issues. However, agencies need to have the courage to develop a policy that they will not attend meetings regarding families unless the family is there, and they need to commit to including family members on all committees.

Most systems that are committed to a collaborative process and that create forums for carrying out the process eventually find it satisfying and productive.

Assuming that people are convinced of the necessity for families to be at the center of both systems development and planning for their own lives, and assuming that the mechanisms to implement this philosophy are put in place, how is it possible to maintain that vision in the face of what may seem like insurmountable obstacles?

In attempting to create a family-designed and implemented system of services in a very rural area, there have been times of incredible satisfaction. There have also been times of painful discouragement. However, it is now difficult to imagine what it would be like for families in our community if they did not have a place to turn in times of stress. Families First is their agency; it is a place where they can feel safe and free from blame and shame. As of this writing, we have offered services to 183 families. Many of these families have been able to improve their quality of life. There has been a significant reduction in restrictive out-of-home placements. And all of these families have been served for the cost of having one child hospitalized for a year.

Maintaining the Vision

Coping With Challenges: Barriers to Implementation

Rurality

There are problems inherent in living in very rural areas, just as inner cities present particular problems. Sparsely populated large geographical areas without any public transportation leave people experiencing severe isolation. The simplest need becomes a tremendous challenge: How do you get a prescription filled? How can you get any respite? How do you get to the doctor or therapist?

Poverty is also endemic to very rural areas; there can be few job opportunities. Isolation is often exacerbated by people not being able to afford telephones. The lack of resources increases people's suffering. Our closest state hospital is three and a half hours away, meaning that children who are placed there often receive no visitors and parents are painfully separated from their children.

Working with families who are multi-stressed in an environment where the resources that they need are unavailable is a constant frustration. One can only be committed to "creative use of existing resources" and to continually working with multi-agency groups to develop new resources. Rural areas also tend to lack a pool of professional people. Areas that do not have a college or university nearby and do not offer cultural opportunities don't attract many well-educated and trained people. This problem is exacerbated in geographic areas that have a harsh climate.

Bureaucratic Challenges

Public policy has a long way to go before it can claim to be truly family friendly. As a family support agency, we are constantly advocating for families to help them deal with systemic injustices. Along with the Federation of Families for Children's Mental Health and other advocacy groups, we firmly believe that no family should ever have to give up custody of a child in order to get services. Laws like the Individuals with Disabilities Education Act (IDEA) are intended to empower consumers, but in their enactment often leave families feeling disempowered. For example, the policy of including parents in Individualized Education Plan meetings is admirable, but parents frequently report feeling ignored and overwhelmed by the professionals at the table. Unfortunately, many other policies and agency mandates also leave families feeling as if systems are irrational and punitive, rather than helpful.

Many systems have developed policies for traditional services that are not appropriate for home- and community-based services. Policies regarding liability, confidentiality, and boundaries that may be deemed necessary for office-based work can create unnecessary obstacles for family-support programs. New standards of professional involvement need to be developed that are respectful of families, but acknowledge the closer and more informal interactions inherent in a family-centered system.

Providers' Reluctance To Work in a True Partnership with Families

It is extremely difficult to witness those providers who treat families with negativity. If one is convinced that individualized wraparound services which enable families to stay together are far superior to removing children

from their homes and communities, then, it is very painful to see families wrenched apart by those who continue to believe that children need to be placed in highly structured environments. Professional/family partnerships can create home-and community-based alternatives that provide structure as well as nurturing. Yet some providers frequently assume that the best way to help a child is to remove him or her from the family. Witnessing families being spoken of disparagingly, watching agencies refuse to share information with participants and exclude families from decisions regarding their lives is distressing to professionals as well as to consumers.

It can also be frustrating to observe a system that incorporates the format for family participation without making commensurate substantive change.

> *I came to a meeting as the parent representative. Nobody talked to me or asked me for my opinion. I didn't understand half of what they were saying. I'll certainly never go back again.*

Developmental Challenges

Any program, just as any life, goes through developmental stages. Inevitably, there are times of discouragement and crises as well as times of success and pleasure. Changing a system takes a very long time, and those who undertake the task of introducing a new paradigm need to have a great deal of patience. People in power rarely give up that power to the underclass easily and willingly. This has been true in the battle for civil rights for minority groups and is equally true for the struggle of adults with mental

illness and families in which there is a child who has emotional and behavioral problems. Schopenhauer, a noted German philosopher, delineated three stages in the acceptance of truth: 1) it is ridiculed, 2) it is violently opposed, 3) it is seen as always having been self-evident. So, too, will it take a long time before an ecological view of the causation of mental illness is accepted and families with children with emotional disabilities are not seen as "dysfunctional."

Maintaining perspective is a constant challenge when attempting to bring about system change. Just as it is necessary to maintain "unconditional care" for families, it is necessary for systems to remain committed to the change process regardless of regressions and frustrations. We need to remember that when an intervention strategy fails, it is necessary to just try another strategy. Also, we need constantly to try to understand the origin of the fear and caution people have regarding change as well as the limits that exist that affect people's and systems' abilities to make changes. An attitude of blaming is no more fruitful when dealing with other providers than with families.

Questions Most Frequently Asked

This philosophy is well and good, but what about really dysfunctional families?

Again, it is more productive to see families as struggling and multi-stressed rather than as "dysfunctional." The concepts described in this monograph have been utilized with the most distressed families, both in rural and urban areas. Kaleidoscope in Chicago and the Family Advocate Project in Vermont are examples. In 1980, a pilot project was established in Addison County, Vermont working with the five families that Social Services identified as the most challenging on their caseload. These were families in which there had been multi-generational patterns of abuse and/or neglect, extreme poverty, and a troubled child was at high risk of being removed from the home. Family advocates worked with these families intensively for a year as case managers doing home-based work, treating families from a strength-based philosophy, and working with them as partners. Follow-up was done for six years; all families were able to maintain their children at home and improved their ability to use community resources.

Recognizing families' strengths, responding to their declared needs, instilling hope, including them in all decision making, sharing information, respecting their cultural values, making individualized wraparound plans with a team including the family, all are efficacious interventions for the most troubled families as well as for those with the most inner or outer resources. Blame and shame are never effective therapeutic tools!

Can people in stress really be expected to plan for themselves? Do they really know what they want?

Yes! People in stress need compassion, nurturing, and encouragement. They may need someone—or a support team—to help them look at their alternatives and make decisions. But they are the only ones who can make plans and who know what they want. If we think of the times that we have all been in crisis, we may realize that we are particularly vulnerable to exploitation and disempowerment at these junctures. With patience, information, and support, professionals can help us make the decisions we need to make for our own lives. Think of receiving the news of a life-threatening illness or experiencing the loss of a loved one. Who, but the individuals involved, should be making the crucial decisions that affect their lives? These decisions need to be made in the context of a person's values. When autonomy is recognized, people's strength to face future challenges is enhanced. Certainly, the same is true for families attempting to cope with their children who are experiencing severe emotional disturbance.

Are you a family advocate or a team player?

This question speaks to the heart of the philosophy of families being at the center of systems development. The family must be seen as an integral part of the team. As the prime purpose of the team is to be an advocate for the family, being a "family advocate" and a "team player" cannot be antithetical. Sometimes the professional people on a team believe that they know what's best for a family. In such situations, when one of the providers

aligns with the family and attempts to help the family achieve the course of action they have chosen, the team feels frustrated and angry at that provider. This scenario is most likely to occur and to create intense feelings when the team believes that it is in the best interests of the child to remove him or her from the home, but the family desperately wants to keep their child. If the providers advocate for home- and community-based alternatives to out-of-home placement, they may be seen as obstructionist. A true family advocate believes that the only way to help a family is to work collaboratively with all the players in that family's life; therefore, by definition being a "team player."

If you advocate so strongly for families staying together, don't you risk having a child harmed? What about child protection?

This is a version of the previous question. The bottom-line answer is that protecting the child has to be the primary concern of everyone working with families. No children should be permitted to remain in a situation in which they are being emotionally or physically abused. Having said this, we need to realize the complexity of the dictum. The emotional cost to children of removing them from their homes, their extended families, and everything that is familiar to them is enormous. Growing up among strangers and/or in an institution is a life that is not normalized and is devoid of the freedom that children in their own homes take for granted—like eating freely when one is hungry or going outside alone to play. Certainly, foster homes and more restrictive placements have been life-saving for children at times.

I loved my foster mother. I stayed in that family for 10 years and still see them all the time.

However, we also need to acknowledge that children can be abused in out-of- home placements: foster homes, group homes, residential placements, and hospitals.

I was allowed to go to school from the hospital. Instead of milk and cookies when I got back, I was strip-searched every day.

My foster father sexually abused me. I will never, never forget it. It will affect me all the rest of my life.

If the amount of money were available to "wrap support services around" a child and family that would otherwise be spent in an out-of-home placement, the vast majority of children could be kept safe in their own homes.

Parents' Advice for Those Attempting to Maintain the Vision

Families First held a feedback session with a group of participants to ask them what they would want to tell people who are developing programs for families. The representatives all held multiple roles with Families First. They all had children experiencing serious emotional disturbance, and they contributed to the agency as board members, staff, or volunteers. Some of their recommendations were:

*Include parents on all committees and boards.

*Establish consumer advisory boards.

*Never design a program without consumer input.

*Involve youth in every aspect of planning and on committees.

*Implement a policy not to hold any meetings regarding families without the family being there.

*Share all information with families.

The parents' recommendations for family members who want to help create family- friendly systems are:

*Express your needs and issues to agencies.

*Get an advocate—Go in twos to special education committee meetings, court hearings, doctors appointments, and hospital admissions offices.

*Begin a support group.

*Hold a social event.

*Tell your story in any forum you can.

*Talk to legislators.

*Convince an agency to sponsor an evening for listening to parents.

(In the Appendix, see *Some Practical Suggestions for Working With Parents as Partners.*)

Vision and Tenacity

Having families truly be at the center of systems development represents a profound paradigm shift. Bringing about systems change is a long-term, challenging effort. While there will inevitably be periods of discouragement, the rewards are enormous. One need only see one family gain self-esteem and improved quality of life to appreciate the benefits of instilling hope, working from strengths, and forming a strong family/professional partnership.

Together, consumers and providers can embark on a journey to create a system of care that is responsive to families' needs and strengths. When a system provides individualized and flexible services, the resulting community will be family-friendly. Both professionals and participants will be enriched by an environment that is respectful and committed to personal growth and mutual caring.

Maya Angelou said, *"The ache for home lives in all of us. The safe place where we can go as we are."*

A parent at Families First said, *"Since I joined into the family of Families First, my world has changed. I've been brought up out of the depression I was in because of what I thought I was doing wrong. I've been able to refocus my energy."*

With vision and tenacity, we can make a difference.

The following attachments are examples of forms, letters, and announcements that Families First has utilized. I believe that the communications we send out are the signature of an organization. It is, therefore, important that they exemplify the organization's philosophy. A family-centered organization's communications need to use language that is easily understood but not condescending, and to express a tone of warmth, respect, and hospitality. The search for the perfect form is as elusive as the search for the perfect mousetrap! I share our efforts with you in the hope that these models may help you to find your agency's own voice.

Materials to Help Get Started - Appendix

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families first

In Essex County

Box 565 Elizabethtown, NY 12932
518 873-9544 1 800 894-7504 for families only

MISSION STATEMENT

Families First is committed to developing a system of care in Essex County for families with children who have serious emotional and/or behavioral problems. We are dedicated to the belief that parents must be involved in every phase of program design and implementation. Services will focus on family strengths, and provide the supports that families say they need. Our goal is to foster a parent/professional partnership throughout child and family serving agencies. Families First intends to serve as a model program for rural areas, and to broadly disseminate its philosophy and practice.

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PARENT PLANNING COMMITTEE RECOMMENDATIONS

1. Families First should function as a parent designed, operated and controlled service system for families who have a child with emotional disturbance.

2. The motto of Families First should be "People Supporting People".

3. There should be a Families First Center, centrally located, with satellite offices that are staffed at least part-time.

4. People receiving services from Families First should be referred to as "participants" rather than "clients".

5. Participants should be able to select, "hire", their Families First service providers; whenever possible more than one person should be available to be interviewed by the family.

6. There should be a patient/client Bill of Rights similar to the one given to patients in the hospital.

7. Families First should have an Advisory Board that is composed of more than 50% parents, the balance professionals.

8. Participants and providers should have an agreement for a trial period after which either can decide to discontinue the "contract". There should be ongoing periodic evaluations as part of every agreement to see if the "match" is successful, and if the service suits the provider and the family.

9. The program should have staff that know all the rules and regulations of agencies so as to be able to inform parents. A position should be established as a "red tape cutter" to facilitate parents accessing services and exercising their rights.

10. Families First needs to stress the importance of being sensitive and attentive to using language that is respectful and inclusive of parents.

11. Priority should be given to parents of special needs children for all staff positions.

12. Need for advocates (case managers):

    - An associate is a person to provide support, coordinate all services, inform parents of rights and resources.
    - Some could be professionals, but also para-professionals and/or other parents. We should try to get Intensive Case Managers if available from the state.
    - Some families need very intensive case management, some just a "little" case management or for a limited amount of time.
    - A parent should be in charge and assure a good match between the advocate and family. The advocate should report to the parent.

13. The program should provide access to a family advocate lawyer.

14. Sex offender and victim treatment needs to be available in the community. There also needs to be adequate staff trained in family therapy. Therapists have to understand the needs of the child and the rest of the family, and address management issues as well as therapeutic issues. Treatment and assessment should be strength based.

15. Training. All staff need to be trained in the family-centered approach. Parents should participate in training of all staff and in the preparation of training materials.

16. Staff should be hired who are open to the family-centered approach. Positions should be available as part-time as well as full-time. There could be a pool of staff, without specific job titles, who are available to meet the family's needs and play the necessary roles.

17. Need for Information and Referral. Establish a resource library of books, videos, and audio tape cassettes for use at the Center for purchase or borrowing. There should be an 800 number for families to use to call the Center.

18. Program should include a home-based option.

19. Families First must have a vehicle and driver to transport people without cars to services — professional, support, and concrete. Volunteers, reimbursed for mileage if they desire, should also be available for transportation.

20. Respite services available to families according to their needs, weekly, weekend a month, annual vacation week, etc.

- Respite can be in a family's own home or in respite provider's home or in community.
- A respite bed in the community could be part of teaching family home, or other space contracted for.
- Arrangements with motels, hotels, bed and breakfasts, where parents could stay — "respitality inns" can provide respite.
- Respite could be used on predictable basis and also available in times of crisis.
- Respite needs to be a "fun" place.
- Children can initiate respite as well as parents.
- Extended family, friends can provide respite.
- Respite can provide something special for the child to do.

Who can provide respite?

- Families First staff or qualified foster parent or someone from the natural support system or a para-professional or volunteer. All respite workers need to be screened, including a police check.
- All respite workers need to receive training. Parents should be active participants in training.
- Training should be half time in classes, half time in the home — include CPR, first aid, non-violent restraint, behavior de-escalation, understanding emotional disturbance, etc.

21. Families First can rate agencies, "accredit" them according to criteria that the Board develops. Accredited agencies can receive a "Families First Seal of Approval" that attests to the fact that they are "Family Friendly". Families First should set the standard

as a democratic, flexible organization with minimal bureaucratic obstacles to service, in which parents are treated as equals with professionals.

22. Parents need to be represented on all child and family planning committees for the county. Since Families First will be hiring parents for as many positions as possible, part of a parent employee's job is to represent Families First at these meetings. Whenever possible, meetings should be held at times that are convenient for parents to attend. Child care and travel reimbursement should be offered.

23. Families First should produce a newsletter that will be widely disseminated to parents of children with problems and to multi-stressed families. It should include child rearing information and information regarding Families First services and other resources.

24. Cash assistance should be available to families through a "flex $ fund" for items such as installing and purchasing a telephone, getting a driver's license, purchasing essential items for children, etc.

25. Crisis services:

    - Families First should have an on-call system with many people available to cover. Good training should be provided for on-call workers—parents, volunteers. They need to know when to refer and to be available to go to homes. Sometimes a team of two people—someone to provide support for siblings—will need to be available.

    - Crisis bed homes should be available for short-term placement if necessary, to provide a "cooling off" period, respite for everyone.

    - In-home 24-hour coverage should be available.

26. Families First should develop a large and varied pool of volunteers. Volunteers need:

    - to be valued;
    - training and support;
    - clear tasks and a clear time commitment; and
    - good communication/notification from Families First staff.

27. Participants should be given an option to contribute time or dollars in exchange for services, now or in the future—but no pressure to do so. Parent support services should be available free of charge.

28. Families First should have a policy of not testifying in court regarding participants, unless subpoenaed. Efforts should be made to quash subpoenas.

29. Families First should not accept mandated participation from courts or agencies.

30. Families First should be available to provide education and training for all agencies and professionals serving children and families, especially courts and schools.

31. All workers, volunteer and paid, should be reimbursed for transportation.

32. The use of interns should be maximized.

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FORM FOR INTERVIEWERS IN ORIGINAL PLANNING PROCESS

Families First hopes to help establish home- and community-based services for families with troubled children in Essex County. The project believes that families know best which services will address their needs and strengths. As a participant in this project, please consider the following questions:

1. Tell the story of what life has been like with your child. Include critical life events and any placements out of the home.

2. What services were most helpful?

3. What services were least helpful?

4. What services do you wish had been available or were available now? If you had a magic wand to create an ideal service system for your family, what would that system look like?

You can use this sheet to make notes for yourself.

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FAMILY INTERVIEW

Parent/s Name/s _____

Address _____

Phone _____ Date _____

How did you hear about Families First? _____

Family members:
Name _____ Age_____ School_____

Problems & Strengths _____

_____

_____

Name _____ Age_____ School_____

Problems & Strengths _____

_____

_____

Name _____ Age_____ School_____

Problems & Strengths _____

_____

_____

What services are your family getting? (DSS? Medical? Mental Health?)

_____

_____

_____

_____

Who do you find helpful in the natural support system? _____

_____

If you had a magic wand, what would you wish for that would be helpful to your family? Many families have told us that they would like the services in the following list. Check those that you would like and then list others that are specific to your family.

Information and referral _____

Parent support — One-to-one _____ Group _____

Sibling support — One-to-one _____ Group _____

Advocate _____

Getting everyone involved with the family together _____

Respite _____

Crisis plan _____

Community friend for child _____

Concrete items (phone, etc.) _____

Other _____

_____

What services might you like to contribute to Families First? _____

Available to talk with other parents on the phone _____

Available to meet with other parents _____

Advocate — attend school meetings, etc. _____

Respite _____

Community friend to child or siblings _____

Provide transportation _____

Office work _____

Other _____

_____

_____

_____

Family's "Story"

Recommendations

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FORM FILLED OUT BY PARENTS FOR CRISIS HOME PROVIDER

ICM CRISIS HOME
Comfort Sheet

Participant Name: _____ Age: _____

Town of Residence: _____ School Dist: _____

Phone: _____ Address: _____

People Living with Youth:

Parents/Guardians (specify relationship): _____

_____

Siblings: _____

_____

Others: _____

Briefly describe youth's strengths _____

Briefly describe youth's issues _____

_____

The following information about the youth may help smooth the transition and stay in a crisis home.

Favorite foods: _____

Favorite toys/belongings: _____

Favorite games/activities: _____

Bedtime hour and evening routine: _____

Wake-up hour and morning routine: _____

Other routines or habits: _____

_____

_____

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CRISIS INFORMATION FORM

FACT SHEET

Child's Name: _____ DOB: _____ Sex: _____
Address: _____ Zip: _____
Telephone: _____

ICM Name: _____ Home Phone: _____
Parent's Name: _____
Address: _____ Phone: _____
Child lives with: _____ Relationship: _____
Legal Guardian: _____

Diagnosis: _____
Medications: _____
Allergies: _____
Health Care Provider: _____
Medical Insurance: _____

Household Composition:

Name	Relationship

Background Information:

_____
_____
_____
_____
_____
_____

Available Crisis Workers:		Available Crisis Homes:	
Name:	Phone:	Name:	Phone:

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Release of Information

Families First believes that family members need to be in charge of their own lives. If you choose to have an advocate work with your family you may want the advocate to help you get new services and/or to help you with the people already providing services. The advocate will not talk to others about your family without your permission and without reporting back to you. You will be invited to attend all meetings initiated by Families First that concern your family.

If you sign this release you are giving permission for Families First to share information with others working with your family such as DSS, doctors, school personnel and for them to share their records and information with Families First.

This release will be in effect as long as you are involved with Families First. You can request that the release be withdrawn at any time.

_____ _____

Signature Date

_____ _____

Signature Date

_____

Address

_____

_____

Phone

SOME PRACTICAL SUGGESTIONS FOR WORKING WITH PARENTS AS PARTNERS

1. If you are designing a program, be sure to include recipient representatives on the planning committee, i.e. youth, parents. Ask them what their needs are, and for suggestions to meet those needs.

2. Program participants need to be part of an ongoing evaluation process. Check in with them and work with them to readjust the program if it is not meeting their needs.

3. Question the usual modalities. Is it possible to deliver services differently to meet a particular family's needs and to utilize their strengths?

4. Whenever you think "problems" also think "strengths". All forms and forums should be strength-based. Support any arena in which families get their strength — friends, family, spirituality, recreation, etc.

5. When making plans with families, don't forget to fully and creatively utilize their natural support systems.

6. Families need to be included in any meeting about them. Family members should help decide whom to invite, what the agenda of the meeting will be, and they should be given the opportunity to chair the meeting.

7. Families should have access to all records concerning them, including assessments and evaluations.

8. If a child is to receive an evaluation, the psychologist should always speak with the parent/s to get information and hear the questions that the parents would like answered.

9. No parent should have to give up custody to get services. If parents do lose custody of their child, they should continue to be included in planning and receive information concerning their child.

10. Be sure to give full information to families concerning their child's disability. Share literature, give references.

11. Remember that parents have prioritized support services as being most helpful. When designing a service plan, don't forget respite, community friends for children, and connecting families to others in similar situations.

12. Don't use "confidentiality" to keep families apart. Ask for permission to share phone numbers and make introductions between people who can provide support to each other.

13. If you have a recommendation to make to a family, phrase it as a suggestion and check it out with them. Don't make assumptions about the family without verifying them.

14. Allow and encourage families to bring an advocate of their choice to meetings.

15. Do not be judgmental about family lifestyles unless a child is in danger.

16. Most important — when you encounter a child with serious emotional problems, <u>do not assume that the family is to blame!</u>

A LETTER TO PARENTS REGARDING WORKING WITH FAMILIES FIRST

We are very pleased that you are considering, or have decided, to work with Families First. We believe that the experience that you've gained living with a child who has emotional or behavioral problems is of tremendous value in your being able to be of help to other parents. Your expertise as a parent is also highly valuable in training and communicating with professionals. You know the realities of the day-to-day challenges, as well as the pleasures, of living with a child with special needs and strengths.

Families First is committed to giving preference to parents in hiring and to having parents be the primary designers and implementers of service.

However, we have learned from experience that being a parent and working as a parent/provider are difficult roles to combine. Some of the challenges parents have had and you might experience are:

1. Boundary issues — When you are receiving service from Families First as well as delivering service, there may be times when you feel confused about your role. You also may find yourself interacting with professionals from other agencies with whom you've interacted as a "client", when you are now in the role of a peer/worker. These overlapping roles can be confusing and stressful.

2. Hope/discouragement — Part of your job with Families First is to help families feel hopeful in the face of discouragement. You can empathize with their frustration, but you want to help them appreciate the potential for things to improve. If you are going through a time of discouragement about your own child it may feel very difficult to project hopefulness to others.

3. Preoccupation with your own "story" — You may feel so absorbed with your own family challenges that it may be difficult at times to listen well to other's stories. Telling your story can be very helpful, especially in sensitizing professionals to families, but it is hard to share very painful and personal things with people you don't know well, and sometimes hard to know how much and what to share.

4. Availability — The stresses and inevitable crises that occur when living with a child with special needs make it hard to be consistently available. There are times when meeting work commitments will be difficult, both literally and emotionally.

5. Anger at the system — Your own anger and frustration with the system of providers may make it difficult to work cooperatively with professionals, and to encourage other parents to work positively with them.

6. Knowing you limits — It may be hard to keep from getting overwhelmed by other's needs, and over involved in their lives. Most parents of children with serious emotional problems are not psychotherapists or doctors (some are!), but it can be tempting to feel that you have to play those roles.

Knowing how challenging it is to work as a parent/professional, Families First will try to provide as clear boundaries and expectations as possible. We offer support and supervision, and want to be responsive to the stresses in your life. We will try to be as flexible and accommodating as we can. If you feel that we are failing, please don't hesitate to let us know. "If in doubt, check it out!"

Everyone at Families First is hired with an agreed-upon trial period. After the period is up, you will have a chance to discuss whether this is the right thing for you at this time in your life. If you would like to do an evaluation sooner, just ask for it.

Having parents work as providers is a new idea. We need your help to make it work. Don't hesitate to give us lots of feedback — positive and/or negative!

Box 565 • Elizabethtown, NY 12932
518 873-9544 • 1 800 894-7504 for families only

OUTREACH FORM

Families First in Essex County, a family friendly program designed by parents, offers support to families who have a child with emotional or behavioral problems. We try to help each family get whatever it needs or wants to make its life better. All services are free.

We invite you to drop into our office on Water Street in Elizabethtown, or to call our 800 number for more information. We would be happy to have someone call you to provide a "listening ear" and tell you what we can offer.

I would like to find out more about Families First. Someone from Families First may call me.

Name _____

Address _____

_____

_____
Signature Date

Referred by:

VOLUNTEER INFORMATION LETTER AND FORM

Dear

Thank you so much for your interest in volunteering for Families First in Essex County. Families First is a new and exciting project that is bringing support to families with a child with serious emotional or behavioral problems. The services have been designed by parents, and parents oversee all the project's activities.

We ask that all volunteers attend two sessions to introduce them to Families First, to get basic information about volunteering, and to learn about children with serious emotional or behavioral problems. After the introductory sessions, you will have an opportunity to talk with the "trainer" to decide together if volunteering for Families First is the right thing for you.

If you do decide to volunteer, you will be working to help a family meet the challenges of living a "multi-stressed" life. Whatever you do, as long as it is offered in a kind and respectful way, will make a big difference to a family. If you are uncertain about anything, you can just ask the parents. There will be a meeting time available two times a month for you to get support and training at the Families First office. You can also call the office anytime you would like to talk with a staff person.

We will try to make good "matches" between families and volunteers. There will be an interview set up for the volunteer and the family. However, we know that sometimes people are not comfortable working together. Therefore, we will always set a time to review the relationship so that changes can be made for things to be better or a decision can be made to end the relationship. We would like you to make a commitment to work with Families First for a year. We will ask you if you would like to continue after the year.

We expect that if you feel concerned or uncomfortable about anything in your volunteer work, you will discuss it with us.

Name _____

Address _____

Phone _____

I will attend the introductory session for volunteers on _____

— SAMPLE LETTER —

STONY WATER BED & BREAKFAST
RR #1. Box 69
Elizabethtown, NY 12932
(518) 873-9125

Winifred Thomas & Sandra Murphy, Innkeepers

January 11, 1993

Louise Cronin
Schroon Lake Inn
Rt. 9
Schroon Lake, NY 12870

Dear Ms. Cronin:

I write to you on behalf of Families First, a newly organized alternative program in Essex County, dedicated to families whose children have severe emotional problems. Our goal is to provide services presently unavailable in this area to enable children to remain in their homes and communities whenever possible. We believe it is vitally important that parents are in control of the services that they receive. Who knows better than they what their families need? One of the things that parents have mentioned again and again is the need for respite...time away from the inordinate demands of a multi-stressed family. In response to that need, Families First is trying now to organize what we call a "Respitality Program". That's where you come in.

We are asking hospitality businesses in Essex County to assist us in providing this badly needed service. As owners of Stony Water Bed and Breakfast in Elizabethtown, my partner and I have been the pilot Respitality Program. Over the last six months we have provided three nights' lodging and breakfast for Families First parents. Aside from our labor, it costs us the price of breakfast. While we don't charge for these stays, we have agreed to take parents only when we won't have to turn away paying guests. It seems to us a way to give a lot for very little. In fact, we feel we have gained as much or more than the parents who've stayed with us. Parents tell us that it has been a renewing and healing experience. We have been most gratified by their response. If a number of businesses are interested in participating in the Respitality Program, each may only be called upon to provide as few as two to five nights a year; of course, you would not be limited to that.

I've enclosed two articles; one will give you more information about Families First and the other will tell you what we have learned from parents. My hope, of course, is that your establishment will become part of the Families First Respitality network. A postcard is enclosed for your convenience in responding. If you would like me, or someone else from Families First, to come and talk to you about this program, please don't hesitate to call or write.

Sincerely,

Winifred K. Thomas
enclosures

families first

In Essex County

Box 565 Elizabethtown, NY 12932
518 873-9544 1 800 894-7504 for families only

OPEN INVITATION TO PROGRAM EVALUATION MEETING

FAMILIES FIRST CELEBRATED ITS SECOND BIRTHDAY IN NOVEMBER. IT IS EXACTLY THREE YEARS SINCE THE FIRST PARENT PLANNING COMMITTEE MEETING WAS HELD. WE ARE COMMITTED TO HAVING EVALUATION BE AN INTEGRAL PART OF OUR WORK. IT SEEMS FITTING THAT WE SHOULD TURN TO THE ORIGINAL PARENT PLANNING COMMITTEE MEMBERS TO ASK THEM TO REVIEW THEIR 32 RECOMMENDATIONS AND SEE HOW WE ARE DOING. WE INVITE YOU TO OBSERVE THEIR CONVERSATION, IN "FISH BOWL" STYLE, AND TO HELP US SET SOME GOALS FOR THE NEXT TWO YEARS.

FEBRUARY 15TH, 1995

3:00 - 5:00

FAMILIES FIRST OFFICE

Join Jim Karr, Laurie Rafferty, Betsey Thomas-Train, Ginny Wood, Fred Hennen, and Bill Ball to look at "How are we doing?"

Please stay for coffee, tea and cookies, and a chance to talk with some staff, board members and participants afterwards!

We would appreciate it if you would let us know by February 8th if you plan to attend. In case of severe weather we will reschedule.

FAMILIES FIRST IS NOW TWO YEARS OLD.
WE'D LIKE YOUR FEEDBACK ON HOW WE'RE DOING.
YOUR OPINIONS COUNT!

PLEASE FILL OUT AND SEND BACK THE ENCLOSED QUESTIONNAIRE.

WE'VE ALSO INCLUDED FOR YOU A LIST OF ESSEX COUNTY PHONE NUMBERS.
WE HOPE THEY ARE HELPFUL NEAR YOUR PHONE.

THANKS MUCH FOR ALL <u>YOUR</u> HELP AND PARTICIPATION!

"THE PARENT IS IN"

You're always welcome to drop in any time at Families First, but we want to announce the official "the parent is in" times. We've hired two parents to host a drop in open house twice a week. Diane will be hosting our drop in time on Fridays, from 10-12, and Marlene will be hosting on Mondays, from 10-12. Stop in and meet them and take the opportunity to chat with another parent who knows what it's like to have a child with special needs. The coffee pot will be on, so come on down.

families first
In Essex County

Box 565 Elizabethtown, NY 12932
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To: Ticonderoga, Crown Point, Schroon Lake area families

From: Naomi Tannen

Date: November 28, 1994

Families First has good news! We have hired Linda Deal as a new staff person to work mostly in the southern part of the county. Linda is a counselor and is also a parent of children with special needs.

Linda and I (Naomi) would like to invite you to a meeting on **Tuesday, December 6th at 7:00 pm** at North Country Community College in Ticonderoga. The meeting will be on the second floor, and the secretary will be able to direct you to the room. You may park in the back and come through the back door.

We want you to tell us how Linda can be of help—Organize social get togethers? Meetings? Invite speakers? Home visits? We need you to tell us what you need and what would be fun, so please plan to come! Call 1-800-894-7504 to tell us if you plan to come and if you need child care or transportation. We look forward to seeing you!

SUPPORT GROUP MEETING

Monday, June 27, 7:00 - 9:00 pm at Families First. Call 1-800-894-7504 for more information.

Families First invites you to a one time support group meeting for adoptive and stepparents. Come and meet other parents who have experienced some of the same issues, struggles, joys, and dreams that you have. Get support for your efforts, benefit from shared brainstorming around any particular issue, and just enjoy meeting parents in the same boat. Dessert and coffee provided!

TEEN SUPPORT GROUP

FOR PEOPLE 12-18 YEARS OLD WHO FEEL THEY NEED SUPPORT BECAUSE OF DIFFICULTIES AT HOME, IN SCHOOL, OR IN ANY OTHER AREA OF THEIR LIVES.

- -

MEETINGS:

Will be held on the 2nd & 4th Thursdays of every month at the FAMILIES FIRST office in Elizabethtown, from **4:00-5:30 PM**

- -

Call Toll Free: **(800) 894-7504** for information.

One of the teens who has planned and will be running the group will be happy to give you more details.

Dates for this winter: December 9 & 23, 1993; January 13 & 27, 1994; February 10 & 24, 1994; March 10 & 24, 1994.

FATHER'S SUPPORT GROUP

All dads welcome, stepfathers,

single fathers, dads with or

without custody.

AT FAMILIES FIRST

MONDAY, SEPTEMBER 12

7:00 - 9:00 PM

Facilitated by John Reynolds

Take the opportunity to meet other fathers, discuss some of the common issues, and get support for your efforts.

July 7, 1995

Dear parent of a preschooler:

The meetings of the Families First preschool for July will be on Friday, July 14 from 10:30 - 12:30, and on Friday, July 28 from 10:30 to 12:30. Preschool has moved to the Daisy Morton Center next to the Fire Hall in Moriah Corners. As usual, lunch will be served from 12:00 to 12:30. Priscilla will also be asking a parent to assist her each time in the preschool; so be thinking about when might be a good time for you to offer your special talents to the group. If a certain date will be best for you, please let Priscilla know. Call the office if you want to come to preschool and need transportation.

Thanks!

SCIP TRAINING!

(STRATEGIES IN CRISIS INTERVENTION AND PREVENTION)

(calming techniques included)

TWO CONSECUTIVE MONDAY EVENINGS.

AUGUST 7TH & 14TH, 6:00 TO 8:00 PM
at Families First in Elizabethtown

Designed for any parent or professional who would like to be able to more effectively defuse a crisis situation.

Led by Michael Karp.

If you have any questions, please call the office at 1-800-894-7504. If you can only make it to one session, please come anyway. Please RSVP to the Families First office by Friday, August 4th.

STRETCHING YOUR FOOD DOLLARS.....

AND YOUR FOOD!

Monday, April 24, 7-9 pm
at Families First

Everybody's got two or three favorite ways to save and stretch on food. The Parent Committee at Families First invites you to come for an evening of sharing your best ways to cut your food expenses. No "expert" speakers offering advice that doesn't fit your lifestyle or income—just other parents sharing common sense, down to earth tips on what works for them.

Bring your best idea — 2 or 3!

Sample ideas might be:

- *bring your favorite cheap recipe*
- *bring coupons to exchange*
- *bring menu plan for a cheap meal*
- *inform people about inexpensive stores*
- *<u>anything you do</u> that saves money on food*

We'll eat treats, talk, have fun, and share ideas. All suggestions will be typed up and shared with those who come. If you can't make it and want the ideas, let us know and we'll send you a copy.

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